Narratives of Neglect

Privileging the priorities of affected persons to support health systems strengthening and the development of equitable people-centred responses to Neglected Tropical Diseases in Liberia

Thesis submitted in accordance with the requirements of the University of Liverpool for the degree of Doctor in Philosophy

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December 2019

Abstract

People-centred health systems are critical to ensure the efficient, effective and sustainable attainment of Universal Health Coverage (UHC). People-centred health systems value a move away from vertical to integrated service delivery that focuses on the needs and values of people. Neglected Tropical Diseases (NTDs) are a diverse group of communicable diseases categorised together due to their geographical spread and neglected status. There is significant evidence of the mutually reinforcing social and economic implications of NTD morbidity and associated disability. However, historically, NTD programmes have been highly verticalized, drawing on biomedical framings of disease control and management, with minimal consideration of social determinants. The multiple and intersecting inequities that shape disease risk and outcome are seldom explored, and there is a lack of data that fully elucidates the illness experience of NTDs by affected persons. However, an emerging paradigm shift within the NTD community suggests the need for better integration with the wider health system, and more holistic approaches to the management of NTDs. This includes disease management, disability, and inclusion (DMDI) strategies that align to the development of people-centred approaches.

The Liberian NTD programme 'Integrated Case Management Strategy', focuses on DMDI for Buruli Ulcer, lymphoedema, hydrocele, leprosy and Yaws, and is designed to establish a person-centred approach to NTD management. Within this thesis, I apply narrative, intersectional and syndemic theory to empirical explorations with the aim of supporting the development of equitable and effective people-centred health systems responses to NTDs in Liberia. I align to capability approaches to disability, by situating health conditions within the broader economic, physical and social environment within which they are located. By discussing necessary health systems responses in relation to chronic disease, morbidity and disability as a result of preventable communicable infection, my analysis suggests that application of syndemic theory to other chronic disease conditions could be beneficial in mainstreaming disability within health systems reform.

I use a qualitative case study approach, that draws on key informant interviews and critical reflections of implementation experience, to explore how changes in health sector governance (NTD policy and programme reform) can support systems change to enable the development of integrated people-centred services. My findings suggest that DMDI can serve as a bridge between the conflicting priorities of NTD programmes conceptualised around disease control, and integrated people-centred health systems focused on holistic care provision.

Using an illness narrative approach, I then interrogate individual experiences of suffering linked to NTD-related morbidity. Narrative and intersectional analysis

enables me to consider how individual's unique positions of power and privilege shape their illness experience and are a powerful tool in documenting experience of affected persons. NTDs create a profound disruption to the lives of people affected, frequently leading to periods of social isolation and mental distress, and require approaches that are transformative and contribute toward redressing existing power hierarchies. The creation of a 'meta-narrative' within this thesis allows commonalities in experiences to be documented to support the generation of chronic care packages that are guided by lived realities and to ensure that the needs and values of affected persons are at the centre of systems design.

Finally, through the application of syndemic theory together with the concepts of structural violence and intersectionality, I draw together analysis at different societal levels to consider how the post-conflict context in Liberia has created a risk environment that shapes negative health outcomes in relation to NTDs and mental distress. Social and structural inequities as a result of conflict and fragility become embodied in varying ways to shape health and disability in Liberia.

Declaration

I, Laura Charlotte Dean, declare that the work in this thesis is my own under the supervision of Sally Theobald and Rachel Tolhurst. At no previous time was this work submitted for a degree or qualification.

Where information has been derived from other sources, or where co-authors have inputted to published papers, this has been indicated in the thesis.

Laura Charlotte Dean

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List of Acronyms

APOC	African Programme for Onchocerciasis Control
BU	Buruli Ulcer
CBR	Community-Based Rehabilitation
CDD	Community Drug Distributor
CHA	Community Health Assistant
CHW	Community Health Worker
CM NTDs	Case Management Neglected Tropical Diseases
COR-NTD	Coalition for Operational Research on Neglected Tropical Diseases
CRPD	Convention on the Rights of Persons with Disabilities
DALYs	Disability Adjusted Life Years
DFID	Department for International Development
DMDI	Disease Management, Disability and Inclusion
ESPEN	Expanded Special Project for the Elimination of Neglected Tropical Diseases
EVD	Ebola Virus Disease
GBD	Global Burden of Disease
GDP	Gross Domestic Product
HIC	High-Income Country
HIV	Human Immunodeficiency Virus
ICF	International Classification of Functioning, Disability and Health
IDM	Intensified Disease Management
K4D	Knowledge for Development
LF	Lymphatic Filariasis
LMIC	Low- and Middle-Income Country
MDA	Mass Drug Administration
MMDP	Morbidity Management and Disability Prevention
MoH	Ministry of Health
NGDO	Non-Governmental Development Organisation
NHP	National Health Policy
NLR	Netherlands Leprosy Relief
NIHR	National Institute for Health Research
NNN	Neglected Tropical Disease Non-Governmental Organisation Network
NTD	Neglected Tropical Disease
PCHS	People-Centred Health Systems
PCR	Polymerase Chain Reaction
PCT	Preventive Chemotherapy and Transmission Control
PRS	Poverty Reduction Strategy
PTSD	Post-traumatic Stress Disorder
PWD	Persons with Disabilities
SDG	Sustainable Development Goals
STH	Soil-transmitted Helminths
TB	Tuberculosis
UHC	Universal Health Coverage

UN	United Nations
USD	United States Dollar
WHO	World Health Organization
YLDs	Years Lost to Disability

Acknowledgements

Firstly, I would like to thank my PhD supervisors- Sally Theobald and Rachel Tolhurst. Sally, your mentorship, guidance, and dedication to my development has and continues to be invaluable. I have learnt so much from you as a role model in promoting the leadership of women in global health both throughout my PhD and the many other projects on which we have collaborated. Rachel, you challenge me intellectually daily, and have supported both my personal and professional development in many ways for which I will always be grateful. My grammar has now greatly improved and my cultural and theoretical knowledge is far deeper. Thank you both for a truly enriching experience, I couldn't have asked for better supervisors to guide and support me through this journey and all of the other work we have undertaken together!

To my number one PhD pal- Rosie- your strength and determination to finish your own PhD through some of the toughest circumstances in life has certainly provided me much needed motivation to finish mine! You are one of the strongest people I know, and going through this process together has made it much more bearable and created a friendship that I will always treasure. To my other PhD pals- Karsor, Amuda, Rozi and Jane- I have learnt so much from my interactions with all of you and look forward to muddling through more research challenges together in the future.

To Imelda Bates for supporting my early development as a researcher, building my confidence to embark on a PhD in the first place, and for always being a listening ear when I need one. To Rachael Thomson, for creating a space within COUNTDOWN for me to begin this PhD and always checking in to see I am doing ok. To Margaret Gyapong for ensuring me that pursuing a PhD in Liberia was the right choice and for your ongoing mentorship. To Julie Irving, for the late nights and early mornings in supporting me to develop my first grant applications and the many laughs along the way. To the everchanging COUNTDOWN team and my other LSTM colleagues, particularly; Susie, Kim, Hayley, Louise, Steffi, Lorelei, Russ, Shahreen, and Helen, for putting up with me talking about this thesis pretty much non-stop, especially over the final few months. A special mention to Kim, for the many travel adventures that have kept me smiling!

To the gender and health group for your critical comments and inputs to many papers and presentations during my time at LSTM. Thanks to my PAP members Russell Stothard and Kate Jehan. Extra thanks to Kate for your friendship and deep theoretical knowledge that you are always happy to share. To Faye, for all your help in the final few weeks, particularly with formatting and making sure I knew where and how to submit.

This thesis would certainly not have been possible without the help and guidance of the Liberian NTD programme team and the COUNTDOWN Liberia family. You have all shown me a great level of care and support while I undertook this thesis and shared with me personal stories that have deepened my understandings of your wonderfully complicated country. To Georgina, Hannah, Princess, Otis, Emmanuel, Anthony, Emmanuel, Zeela, Tia, Natt, Fred, Olive and Alice, thank you for keeping my spirits up on some of the worst journeys of my life, always making me laugh, and always persevering to ensure our work was completed. To Karsor for your patience through my constant questioning, willingness to always think about things differently, and unfounded belief that this thesis would support the strengthening of the case management programme- I hope at least some of it is useful. To Anna, Maneesh and Lazenya, for showing me around Monrovia and our shared love of ginger chicken wings. Special and most thanks to Gartee, having your support throughout data collection was invaluable- I learnt so much from you about life and Liberia- and for this I will always be grateful. You are a fantastic health worker and researcher and a true asset to the health system of Liberia.

Thanks to my parents- Jackie and Bob- for teaching me that your best is always good enough, sacrificing so much so that I could pursue higher education and for instilling in me a work ethic that is certainly necessary to finish a PhD. To Becky, for always being there as a sister and a friend.

To Mark, your patience over the last 4 years has been unwavering. Your love and support in all that I do means more to me than you could possibly know, and a little piece of this PhD certainly belongs to you! Thank you for everything, always.

Finally, but most importantly, I would like to thank all the participants who took the time to share their stories with me. This thesis would not have been possible without the time, honesty, and trust that it took for you to share such personal challenges. I will do all that I can to use the strength that you showed in sharing your experiences to support change in Liberia.

This research was possible due to funding from the UK Department for International Development through the COUNTDOWN programme.

Chapter 1: Introduction

1.1 Chapter Overview

This chapter provides background information to situate this thesis within wider Neglected Tropical Disease (NTD) discourse and outlines key concepts or debates surrounding people-centred health systems, equity, gender and intersectionality- which are central framings within this thesis. It then moves on to provide the study rationale and introduces the aims and objectives of the thesis, before providing an overview of the thesis structure and the context of the complex socio-political history of Liberia.

My research was closely aligned to the COUNTDOWN consortium. COUNTDOWN is a seven-year multidisciplinary research programme, led by the Liverpool School of Tropical Medicine, and funded through the UK Department for International Development (DFID)[1]. COUNTDOWN's work focuses across four countries in sub-Saharan Africa - Cameroon, Ghana, Nigeria and Liberia - and brings together Neglected Tropical Disease (NTD) researchers, policy makers, practitioners, and implementation research specialists, to support the scale-up of appropriate interventions against NTDs amenable to preventive chemotherapy. COUNTDOWN aims to increase the effectiveness of NTD programmes, with a focus on reaching poor and vulnerable groups and highlighting inequities, to support more people to access appropriate interventions and receive necessary treatments. More detail on COUNTDOWN and my position within it is found in section 3.1 of this thesis. The findings from this research have also led to the attainment of an NIHR funded award in Liberia, as well as two small grants through the Coalition for Operational Research on NTDs, one in Liberia and one in Nigeria. All of these new awards are designed to support health systems to strengthen their response to be able to support in meeting the needs of people affected by NTDs, and are guided by recommendations provided in thesis Chapter 8 (8.3).

[1] For more information please see: https://countdown.lstmed.ac.uk/

1.2 Background to the Study

1.2.1 Neglected Tropical Diseases

Neglected Tropical Diseases (NTDs) are a diverse group of communicable diseases categorised together due to their geographical spread and neglected status (Hofstraat and van Brakel, 2016). NTDs frequently impact the most marginalised and impoverished people and have multifaceted manifestations that can be the cause of increased mortality and morbidity amongst vulnerable populations (Reidpath et al., 2011). The 2013 Global Burden of Disease Study (GBD) suggests that there are 2 billion prevalent NTD infections resultant in approximately 25 million Disability Adjusted Life Years (DALYs) (Herricks et al., 2017). However, current estimates in NTD disease burden through DALY calculation focus solely on the pathology and contribution of disease sequalae to morbidity and premature mortality, neglecting to consider associated psycho-social burden, associated stigma of morbidity and links with poverty (Ton et al., 2015). Impacts of chronic NTDs include inability to work, reduced employment or livelihood opportunities, catastrophic health expenditure, and reduced societal roles and participation due to resultant stigma, all of which have significant emotional burden and can lead to disability. This suggests that the global burden of NTDs is likely much higher than is currently estimated (Ton et al., 2015).

Throughout the last three decades, NTDs have received increased attention and funding due to sustained advocacy efforts(Dean et al., 2019a). Advocacy arguments and programme momentum has been targeted towards the control and elimination of selected NTDs by 2020, with specific goals and targets outlined in the World Health Organisations (WHO) 2020 roadmap for implementation, *'Accelerating Work to Overcome the Global Impact of Neglected Tropical Diseases'*(World Health Organization, 2012). Most recently, NTDs have been prioritised within the Sustainable Development Goals (SDG) indicator 3.3 'to end the epidemic of NTDs by 2030', as well as being linked to other SDG indicators associated with universal health coverage (UHC), water and sanitation (Fitzpatrick and Engels, 2016). Next year will see the launch of WHO's Neglected Tropical Disease Roadmap to 2030 which will outline new guidelines and targets for disease control and elimination based on

programmatic analysis throughout the preceding plan period. This thesis seeks to support the development of more progressive and inclusive people-centred NTD programmes as the NTD community transitions its focus from 2020 to 2030.

WHO's roadmap for implementation identified and prioritised two major strategies through which NTD programmes were expected to reach 2020 control and elimination targets, these were Intensified Disease Management (IDM) and Preventive Chemotherapy and Transmission Control (PCT)(Organisation, 2015 , World Health Organization, 2012). IDM focuses on disease elimination as a public health problem by prioritising the management of disease within the primary health care system. Whereas, PCT focuses on the use of safe and effective medicines to prevent disease by interrupting transmission through the implementation of large scale, population-based drug distribution, usually termed Mass Drug Administration (MDA)(World Health Organization, 2012). The diseases of focus for each of these strategies are highlighted in Table 1[2]. Stage of implementation of IDM and PCT varies by disease and region within and across countries (Organisation, 2015). However, PCT interventions have been prioritised and as a consequence are frequently more established, becoming the primary public health intervention targeting NTDs globally (Molyneux et al., 2018).

Table 1: Neglected Tropical Diseases Clustered by Control Strategy

Disease Type	**Disease Name**
Preventive Chemotherapy and Transmission Control (PCT)	• Dracunculiasis, • Lymphatic Filariasis (LF), • Onchocerciasis, • Schistosomiasis, • Soil-transmitted helminths (STH) • Trachoma
Innovative and Intensified Disease Management (IDM)	• Leprosy, • Buruli ulcer, • Chagas disease, • Human African Trypanosomiasis,

[2] Some PCT diseases, e.g. lymphatic filariasis also require disease management strategies due to the chronicity of clinical manifestations, for example lymphoedema and hydrocele.

	• Leishmaniasis • Yaws

Due to the high coverage rates that PCT interventions need to be successful, coupled with grassroots models of community engagement that rely on community volunteers to distribute medicines, health system responses to NTDs amenable to PCT have been described as a 'litmus test' for UHC(Fitzpatrick and Engels, 2016, Organisation, 2015). Furthermore, indication that MDA campaigns can and have reached areas where other health services cannot, has resulted in them being defined as an equity tracer for monitoring the attainment of the SDGs(Fitzpatrick and Engels, 2016, Smith and Taylor, 2016, World Health Organisation, 2017). However, despite many successes on the journey toward 2020, and the recognition of the strengths of PCT service delivery internationally, limited consideration has been given to the equity of MDA approaches within and between countries and diseases(Dean et al., 2019a). There is a need for new approaches and analyses to ensure equity in programme delivery moving forward and to increase the focus on those populations for whom NTDs will never be fully eliminated, due to the life-altering morbidity and disability they have left behind. Thus, innovative and intensified disease management strategies demand greater prioritisation.

Historically, within NTD policy, programming and research, medicalised approaches have been prioritised with limited consideration of the social impacts. For example, both IDM and PCT 'manage' NTDs in a way that is preferred or perceived to be best practice from the view point of medical practitioners and other global health professionals, with limited consideration of the priorities of affected persons. One of the main focuses of UHC is to establish progressive mechanisms[3] that support the

[3] Progressive realisation of Universal Health Coverage specifically relates to supporting countries to make incremental decisions about the implementation of high priority services. This may include: adding new services into essential health packages; expanding coverage of existing priority services; or reducing out-of-pocket payments for existing priority interventions. Service prioritisation is not straightforward and may include challenging trade-offs between services that are cost-effective, target severe diseases or disadvantaged populations and provide financial risk protection. Ideally such decisions would be guided by principals of fairness and equity(BALTUSSEN, R., JANSEN, M., BIJLMAKERS, L., TROMP, N., YAMIN, A. & NORHEIM, O. 2017. Progressive realisation of universal health coverage: what are the required processes and evidence? *BMJ global health,* 2**,** e000342.)

provision of an essential package of health services that prioritises reaching the most vulnerable first as opposed to just extending routine service delivery (Baltussen et al., 2017). Therefore, given that the majority of NTDs do not cause death but do cause disability amongst some of the world's most vulnerable populations, how can NTDs be truly described as a 'litmus test' for UHC or an equity tracer within the SDGs if the views and needs of persons affected by NTDs are not prioritised? Thus, a more holistic approach to the management of NTDs is needed that mainstreams disability and supports the physical, psychological and social needs of affected persons (van 't Noordende et al., 2016) to ensure progressive realisation of UHC and the SDGs. Without a reorientation of approaches, people affected by NTDs are likely to continue to be 'left behind' on the journey to 2030.

The NTD Non-Governmental organisation Network (NNN)[4] reports a shift in thinking amongst NTD practitioners and associated policy dialogues to focus on strategies that promote the more holistic concept of disease management, disability and inclusion (DMDI) (Mieras et al., 2016). 'Disease management' focuses on the need for medical approaches to manage the morbidity associated with NTDs. 'Disability' is included to emphasise that disability is a consequence of impairment or condition within a particular context and to ensure that social manifestations and other often non-medicalised consequences such as stigma and mental health are not ignored. Finally, 'inclusion' is intended to reflect the need to include people living with the consequence of NTDs in programme design and society more generally (Mieras et al., 2016). In combination, DMDI aims to ensure provision of a full continuum of care for individuals affected by NTDs, rather than one which is dominated by medical approaches and marginalises lived experiences.

1.2.1.1 Existing Health Systems Responses to NTDs

Despite apparent similarities and logic for the co-implementation of NTD interventions focused on specific diseases, NTD interventions have largely been

[4] The Neglected Tropical Disease Non-Governmental Organisation Network (NNN) is a global forum for NGOs to contribute to the global control, elimination, and management of consequences of NTDs outlined within the internationally agreed World Health Organisation NTD Roadmap. https://www.ntd-ngonetwork.org/about

heterogeneous in approach(Liese et al., 2010). In part, this is due to: challenges in the methods that are used to implement interventions (e.g. some may use community-based delivery mechanisms whilst other use school-based); differing epidemiological goals and denominators when measuring effectiveness of interventions; and a lack in prioritisation or pooling of funding and approaches within and between donors (Mathieu and Knipes, 2013). Hopkins (2016), describes a recent shift within NTD programming suggesting they are now considered in a more integrated way as opposed to disease specific programmes(Hopkins, 2016). The closure of the African Programme for Onchocerciasis Control (APOC) and the initiation of the Expanded Special Project for the Elimination of NTDs (ESPEN) epitomises this shift. Some advances have also been made in generating more standardised measures and frameworks for monitoring programme coverage and the NNN have focused on advocating for pooled and more harmonised funding, as well as collaborative programme design across sectors and agencies to develop and implement comprehensive NTD programmes. Despite best efforts to promote harmonisation for co-implementation, a lack of evidence exists for best practices and a persistent lack of understanding of the practical implications related to their implementation remains. Co-implementation with other vertical disease programmes beyond those associated with other NTDs, such as those focused on HIV, Malaria and TB has also seldom been explored or prioritised.

Beyond co-implementation there is also a lack of integration of NTD programmes with the broader health system. This is particularly important in considering the long-term sustainability of gains made toward control and elimination of NTDs through vertical disease programmes. Integration with the broader health system is essential when thinking about the scale-up (i.e. to reach more members of the population or to expand services to a wider area) of existing interventions(Marchal et al., 2011). Without this, there is a risk of establishing parallel systems that do not strengthen or utilise capacities of existing health systems, which again creates significant bottlenecks when thinking about long term implementation of NTD interventions(Marchal et al., 2011). Given the heavy reliance on donor funding for NTD control, this would likely involve further advocacy and planning regarding the

need for integrated programming for NTDs. Furthermore, robust health management information systems would need to be developed due to the increased complexity in reporting intervention effectiveness on the basis of horizontal programmes.

In relation to DMDI, little information presently exists about the best strategies to promote integrated DMDI across disease programmes(Hopkins, 2016). Typically, DMDI has been viewed as the responsibility of the primary health care system and so has been neglected by vertical NTD programmes specifically focused on PCT. However, primary health care facilities are often both under-skilled and under-resourced in their ability to deliver DMDI interventions and this has left a gap in the provision of such services (Molyneux et al., 2018). One of the key priorities of the ESPEN network is DMDI(World Health Organisation, 2019), which suggests a step in the right direction toward co-implementation and integration of DMDI services. However, without data that establishes strategies to facilitate co-implemented or integrated DMDI, efforts are likely to be unsuccessful. Critically, in relation to DMDI there is a lack of information that explores illness experience relating to differing NTDs and therefore little is known about the similarities and differences between such experiences. Without such information it is not only difficult to understand what strategies are necessary for DMDI from the perspective of individuals affected by NTDs, it is also difficult to elucidate the feasibility and acceptability of combined interventions. Shifting focus towards increased cohesion between NTDs and the health system, combined with demands for more holistic DMDI, therefore presents the opportunity to consider the feasibility and acceptability of co-implementation and integration from the perspective of affected individuals, with a view to investing in more sustainable solutions.

1.2.2 People Centred Health Systems and Chronic Care Delivery

Universal health coverage and the development of people centred health systems are thought to be mutually reinforcing ideals, as both prioritise the right to health through integrated and targeted approaches that favour the needs of the most vulnerable(Sheikh et al., 2014a, Sheikh et al., 2014b, World Health Organisation, 2015). The right to health in this instance aligns to collective dimensions of rights as

opposed to individualistic approaches. Collective action and social solidarity is viewed as essential to the art and science of promoting and protecting good health and the realisation of rights that are collective in nature (London et al., 2014). People-centred health systems provide:

> 'an approach to care that consciously adopts the perspectives of individuals, families and communities and sees them as participants as well as beneficiaries of trusted health systems that respond to their needs and preferences in humane and holistic ways' (World Health Organisation, 2015p11).

Critically, people-centred health systems are organised around people's health care needs and expectations as opposed to diseases, and deliver services in a way that ensures a continuum of care throughout the life-course (Starfield, 2011, World Health Organisation, 2015). People-centred care becomes a critical pillar of primary health care and involves ensuring that health promotion, disease prevention, diagnosis, treatment, disease management, rehabilitation and palliative care services are equally prioritised (World Health Organisation, 2015). By embracing the human character of health systems (Sheikh et al., 2014b), their organisation and focus moves away from traditional models of care characterised by bio-medical models of health and healthcare (see section 2.2) (Ferrer et al., 2014). However, shifting systems to respond in this way is challenging, particularly in low- and middle-income countries where vertical disease programmes, such as those targeting NTDs through PCT, TB, Malaria, and HIV, have dominated systems design, development and values (Marchal et al., 2011, Mounier-Jack et al., 2017). In these contexts, clinical or intervention guidelines tend to be focused on one condition at a time and prioritise medicalised disease management with limited focus on the relief of individual suffering (Starfield, 2011, Mounier-Jack et al., 2017).

Longitudinal care is also essential in the management of chronic conditions, such as life altering impacts of NTDs (e.g. lymphoedema), as it enables trusting relationships to be established between individuals and professionals, and supports primary health care services to become orientated around life-course approaches, not only

as sites for resolving new or acute problems (Ferrer et al., 2014, Ku and Kegels, 2015, Starfield, 2011). However, there is a tension between chronic patient-centred care and person-centred health systems due to different underlying conceptualisations; patient-centred care is disease focused whereas people-centred systems see the person as a whole (Starfield, 2011). Nevertheless, both respond to feedback from service beneficiaries as to the impact and outcome of the service and prioritise the most important concerns of affected persons in providing care. Person-centred care expands the focus of the prioritisation of need to consider wellbeing outside of disease condition (Santana et al., 2018). Thus, both chronic care delivery and the development of people-centred health systems often grapple with the same challenge of how to ensure inclusion of the values of affected persons in designing a service that responds to need (Starfield, 2011). Furthermore, in the management of chronic conditions, person-centred care over time becomes as critical as patient-centred interactions, to ensure responsiveness to the problems and broader health and wellbeing concerns of affected persons as they experience them, not just as defined by healthcare professionals (Starfield, 2011).

People-centred health systems view individuals, communities and health workers as co-producers of health care, as systems move to put people and families at the centre as opposed to health providers (see Figure 1)(Goodwin, 2016, World Health Organisation, 2015, Goodwin, 2014). This can involve collaborations outside of the health sector as the cultural and social right of everyone to a universal minimum standard of health and health care is promoted. However, approaches to the development and implementation of people-centred health systems are not uniform, rather they are shaped by the socio-economic, cultural, geographic, political and health systems realities within which they are embedded (World Health Organisation, 2015). Systems must adapt to meet a range of challenges to support the development of strategies that seek to improve health care access, and encourage universal coverage through the provision of primary and community-based care that prioritises improvements in quality of life (Goodwin, 2014).

Participatory governance mechanisms that recognise the roles and relations of all systems actors become central to the success of people-centred health systems

(Abimbola et al., 2014). It is essential that active approaches to the engagement and empowerment of people are prioritised to reduce the focus of paternalistic care delivery, and support a new form of partnership between health systems, people and populations (Goodwin, 2016). Systems transformation becomes a long-term processes that requires political will and leadership and which supports mutual reinforcing processes of bottom-up demand driven measures as well as top-down supply driven reforms (Montenegro et al., 2012). Efforts to make health care more person-centred have been shown to be more successful when linked to other drivers for change, for example, in addressing chronic diseases or improving equity in healthcare (Montenegro et al., 2012). Thus, considering how to align equity related discourse with the development of DMDI interventions designed to promote change toward more people-centred systems is beneficial.

1.2.3 Health Equity, Gender and Intersectionality

Inequities in health are described as differences in health that are 'unnecessary, avoidable, unfair and unjust' and addressing inequities presents many moral, ethical and political obligations(Braveman and Gruskin, 2003). Movements advocating for UHC have revitalised the focus on better understanding and addressing inequities within global health, particularly in relation to the structure of health systems, the utilisation of health services, and in experiences of (ill) health and wellbeing (Allotey and Gyapong, 2005, Morgan et al., 2016). A key operational definition of health equity is:

> *'the absence of systemic disparities in health (or in the major social determinants of health) between social groups who have differing levels of underlying social advantage/disadvantage- that is, different positions in a social hierarchy. Inequities in health systematically put groups of people who are already socially disadvantaged (for example, by virtue of being poor female, and/or members of a disenfranchised racial ethnic or religious group) at further disadvantage with respect to their health; health is essential*

to wellbeing and to overcoming other effects of social disadvantage'(Braveman and Gruskin, 2003p254).

Thus, effectively addressing inequities in health requires in-depth understandings of the reasons why such inequities exist as determined by interweaving social and structural power differentials that shape the social determinants of health. Equity in health is grounded in the ethical principle of distributive justice, and it is challenging to directly analyse and measure(Braveman and Gruskin, 2003). Globally, analysis of equity in health has frequently prioritised poverty as a key analytical lens. Additionally, the 1995 Beijing Platform for Action promoted 'gender mainstreaming' as a systematic way to respond to increasing recognition of gender inequities within health (Hankivsky, 2005). However, interactions between gender and poverty, as well as other axes of inequity such as dis/ability, and their impact on health and wellbeing are infrequently explored.

Gender is a socially constructed hierarchical power relation which is deeply entrenched within the historical and cultural fabric of societies and institutions (Connell, 2009). Interpretations and construction of gender are fluid and vary across contexts and through time; this is in direct opposition to binary categories of sex such as male, female and intersex that are shaped by biological characteristics(Morgan et al., 2016, Sen and Östlin, 2008). Gender is also relational; consideration of how gender as a multi-dimensional power relationship operates in a complex web of institutions is critical. This is particularly important in considering how men, women and people of other genders interact with each other as well as social structures such as the health system (Kleinman, 1980). Gender and associated power shapes experience of disease and illness and should be considered in developing person-centred responses to these phenomenon (Morgan et al., 2016, Sen and Östlin, 2008, Sheikh et al., 2014a, Standing, 1997). However, health research, particularly research centred around the development of person-centred health systems, frequently neglects to consider the social and relational components of gender and has prioritised a focus on women's health (Connell, 2012, Morgan et al., 2016, Standing, 1997). This is problematic in developing gender transformative responses to the experience of ill-health (which are often mediated through health systems) as it

neglects the roles and needs of men and boys in promoting social change (Connell, 2012).

'Gender mainstreaming' theoretically focuses on appreciation of gender issues within policy, programming and systems design so as to reduce inequities in service access and provision based on gender(Hankivsky, 2005). However, critiques of gender mainstreaming (and also gender analysis), indicate that its success has been uneven and partial and has neglected developments in feminist theory that focus on complex social circumstance that shape gender differences (Hankivsky, 2005, McCall, 2005). Frequently, however, this too has led to a focus on gender analysis with limited consideration of gender as a socially constructed concept that varies through space, contexts and time, as individuals construct roles and identities which are shaped by broader political, social, cultural and economic factors(Dean et al., 2019a). This is representative of dominant models of gender analysis, within which fluidity of gender beyond the separation of women and men is lacking, as well as an appreciation of how gender interacts with '*wider structural inequalities'* to create differing experiences of power and privilege in relation to health and wellbeing (Tolhurst et al., 2012). Thus, focusing on gender in isolation, will not lead to equitable service delivery (Connell, 2012, Connell and Messerschmidt, 2005, Tolhurst et al., 2002), compromising attainment of UHC and development of equitable people-centred health systems. Better understandings of structural inequalities and their different manifestations in relation to social configuration and location are essential to be able to design and develop health systems that are more equitable and responsive to varying axes of power(Hankivsky, 2012, Tolhurst et al., 2012).

Within academic discourse, western feminist theories are often pervasive. However, African feminism(s) presents a wide variety of innovative activist and academic projects that become critical cites of resistance for African women (Guy-Sheftall, 2003). There is a need to re-consider what this means for 'global feminism' and the application of gender analysis within diverse African settings. Western and African feminisms are not necessarily oppositional, rather it is important to consider less dominant approaches and understandings within the application of feminist theory to consider particular spatial and epistemological locales (Cruz, 2015). African

feminism is fused with liberation from multiple forms of oppression, particularly, slavery, colonialism, neo-colonialism, racism, poverty, illiteracy and disease (Guy-Sheftall, 2003). Women in Africa have frequently bore witness to the worst aspects of militarism, due to long and multiple conflicts and military regimes on the struggle to independence. These periods have ruined lives, disrupted livelihoods and left legacies of abuse, violence and gender inequality (Mama, 2012). African feminist scholars have historically focused on these specific issues of concern to address gender imbalances and power, but also to consider questions of basic needs and survival (Cruz, 2015). Liberia is no stranger to war and the associated links between male domination of political and economic arenas is marked (Mama, 2012). However, Liberia also has a unique feminist history (as further discussed in section 2.2) that has supported an ongoing resistance movement which is led by African feminists as they seek to challenge the multiple jeopardies experienced by the women of Liberia(Fuest, 2008). Consideration of indigenous forms of feminism in Liberia are critical to the gendered analysis presented within this thesis. Acknowledgement of my position as a white-European and the limitations this presents for this type of analysis was also essential and is discussed further within sections 4.2.5 and 4.11. (Nkealah, 2006).

Intersectionality is a theoretical orientation that underlines research and activism that seeks to "*move beyond single or typically favoured categories of analysis (e.g. sex, gender, race and class) to consider simultaneous interactions between different aspects of social identity, as well as the impact of systems and processes of oppression and domination*"(Hankivsky et al., 2009p3). In African feminism such consideration of multiple analytical categories and their interconnections can be described as 'holism' that allows for sense making of societal domains and placing particular emphasis on the need to consider individual lives in relation to the whole (Cruz, 2015). Intersectional theory originates in black feminist thought and although it doesn't privilege analysis by gender it is important to acknowledge that it is inherently feminist(Crenshaw, 1991). Intersectionality provides the opportunity for a cumulative exploration of individuals' micro-positioning within macro structural factors (Collins, 2002) through consideration of multiple interconnecting factors

allowing for movement beyond gender as a primary form of oppression (Hankivsky, 2005, Hankivsky, 2012, Tolhurst et al., 2012). Whilst in some instances gender may be the primary axis through which individuals frame their lives, intersectionality provides an opportunity for multi-faceted analysis focused on how factors of privilege and penalty may alternate between contexts or occur simultaneously in relation to different axes of power in the same context (Hankivsky, 2012). Critically, it is not an additive exploration; rather it emphasises the subjective and complex nature of human characteristics and experience that can be based on socially constructed categorisation such as; race, ethnicity, gender, age, sexuality, ability, disability and class.

1.3 Rationale for the Study

The majority of NTD programmes and research studies take a top-down approach to implementation and apply international strategies and guidelines with limited consideration of adaptation for context and the priorities of intended service beneficiaries. People- centred approaches to health systems or intervention design, demand that the broader social and structural determinants of health and well-being are considered, as well as prioritising the values and needs of the most marginalised. In order to challenge ongoing top-down approaches to NTD service design and delivery, prioritising the perspectives of people affected by NTDs within this thesis was essential. This supports better understanding of the needs and values of affected persons and supports to make bottom-up recommendations of how to ensure needs are met in ways that are both appropriate and acceptable.

Liberia is one of the first countries globally to develop an integrated person-centred approach to the management of a number of its endemic NTDs (leprosy, Buruli ulcer, Yaws and clinical manifestations of lymphatic filariasis- lymphoedema and hydrocele)(Ministry of Health, 2016). Prior to October 2016, there was no clear DMDI strategy; disease management associated with NTDs was completed on an *ad hoc* basis. Following the Ebola outbreak, together with their technical and funding partners the NTD programme in Liberia launched the 'Strategic Plan for Integrated Case Management of Neglected Tropical Diseases (NTDs) 2016-2020' (Ministry of

Health, 2016). This strategic document was designed to respond to the significant NTD burden in the country, exacerbated by decades of civil unrest and the recent Ebola outbreak and is embedded as part of the country's National Health Policy (Ministry of Health, 2016). Specific strategic objectives of the plan are detailed in Box 1.

Despite this significant step in developing and launching the integrated disease management plan, there is still minimal evidence from the perspectives of the individuals living with NTDs and their families in terms of what the plan should include and how it should be implemented in Liberia. Furthermore, the integrated disease management plan currently excludes onchocerciasis which is known to have severe associated physical and psychological morbidity. Onchocerciasis is often excluded from such strategies on the basis of rapid reduction in incidence of the disease and its primary classification as a PCT disease. However, there are still large numbers of individuals living with lifelong morbidity as a result of onchocerciasis who should be included in DMDI programming. This is particularly important in Liberia which is identified as still having one of the highest prevalence of onchocerciasis worldwide (22,739 per 100,000 population)(Herricks et al., 2017).

As the Ministry of Health embarked on the implementation of the integrated disease management plan to assesses its feasibility, this presented a unique opportunity to consider the perspectives of affected individuals. This thesis was designed to explore potential synergies and diversities in illness experience between varying NTDs from the perspective of individuals and their families. Through close collaboration with the Ministry of Health in Liberia[5] the study was designed to support further development of the case management plan to elucidate what practical and feasible steps could be put in place to allow for integrated DMDI from the perspective of people affected by NTDs.

[5] Specifically, the National Neglected Tropical Disease Programme, including the National Programme Manager and relevant disease programme co-ordinators (e.g. case management, onchocerciasis, and lymphatic filariasis) and regional supervisors.

Box 1: Strategic Priorities and Outcomes of Liberia's Strategic Plan for Integrated Case Management of Neglected Tropical Diseases 2016-2020

SP1. Government ownership, advocacy, coordination, and partnerships strengthened for integrated NTD case management

- Government ownership of Integrated NTD program in Liberia by 2021
    - Partnership for the control, elimination and eradication of NTDs strengthened at all levels as well as international levels
    - Increased visibility and profile of NTDs interventions (Case Management and MDA) that will lead to control, eliminating and eradication at all levels

SP2. Resource mobilization and planning for results in integrated NTD case management increased

- Resources mobilized to support entire NTD Results Based Plan and Budget
    - NTDs integrated into all relevant national policies and planning
    - Increased community awareness and engagement in CM NTDs

SP3. Access to interventions and treatment improved and system capacity built for integrated NTD case management scaled up

- NTD diagnosis and treatment accessible to all people in Liberia by 2021
    - Supply chain for CM NTD treatment and management strengthened
    - Increased community access to NTD CM treatment
    - Existing MDA campaigns utilised to identify suspected CM cases
    - Ganta established as Centre of Excellence for NTDs

SP4. Monitoring, surveillance and operational research enhanced

- Integrated monitoring and surveillance implemented through the MOH
    - Improved surveillance for CM NTDs
    - Evidence based monitoring system established and operational

1.4 Thesis Aims and Objectives

The overarching aim of this thesis is to support the development of equitable and effective people-centred health systems responses to Neglected Tropical Diseases in Liberia. This thesis takes a holistic approach to health and wellbeing to achieve the following objectives:

1. To understand the Liberian health systems response to chronic disease and disability with a specific focus on onchocerciasis, Buruli ulcer, lymphoedema, hydrocele and leprosy.

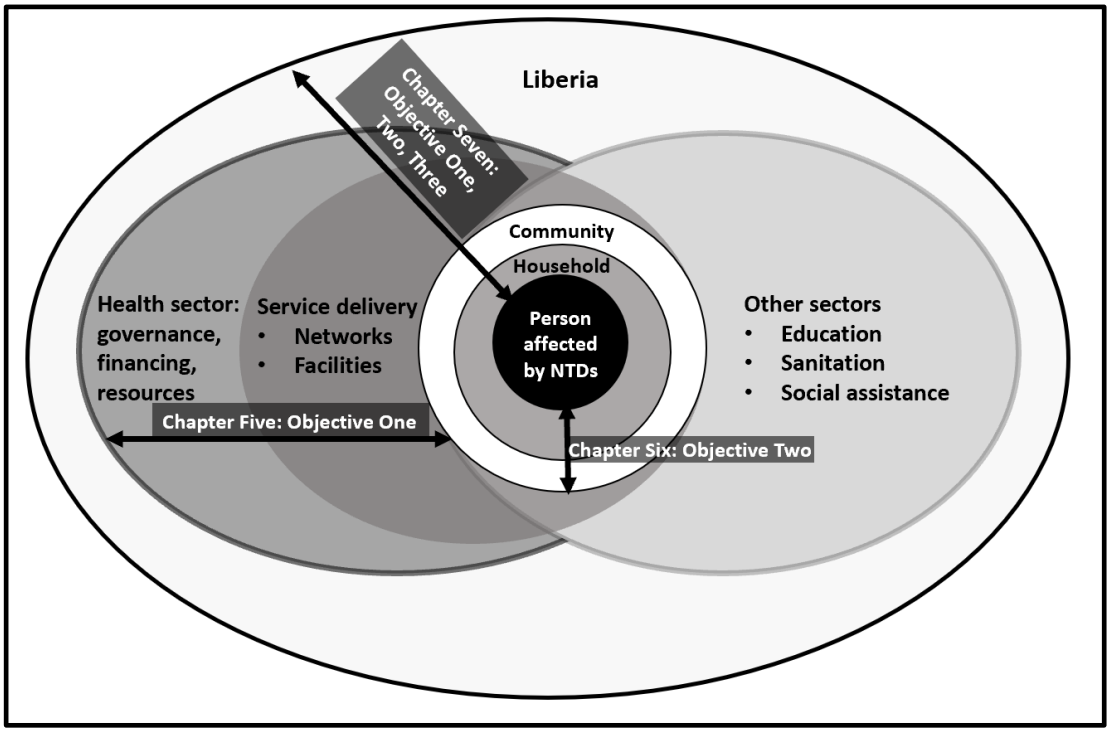
2. To understand individual experience of living with one or more of selected NTDs from the perspective of affected individuals and members of their household with a focus on how this varies by differing axes of inequality such as age, disability and gender.

3. To elucidate what medical, social and economic strategies would allow for more equitable and effective support and management for selected NTDs from the perspective of affected individuals, with exploration of how such strategies could be integrated between diseases and within the wider health systems response to chronic disease and disability.

The NTDs of focus in this study are; leprosy, Buruli Ulcer, clinical manifestations of lymphatic filariasis (lymphoedema and hydrocele) and onchocerciasis due to their endemicity and priority status within Liberia. Further detail on the rationale for the inclusion of these diseases is provided in section 4.3.1.

This research is located within the constructivist paradigm as described in Chapter 3 (3.2) and presents an analysis structured in three parts to meet the thesis aims. Constituent parts of the analysis are aligned to WHOs conceptual framework for people-centred and integrated health services as shown in Figure 1.

Figure 1: Overall Study Framing (adapted from (World Health Organisation, 2015)



Firstly, within Chapter 5, I draw on key informant data to consider how a change in ***health sector governance*** (through the roll out of the integrated case management plan) supports the development of equitable people-centred **service delivery** in response to NTDs and health systems strengthening, and to what extent social relationships influence the successes and failings within this process. Secondly, within Chapter 6, I draw on narrative analysis and intersectional analysis and the theoretical perspectives that shape both of these, to put people at the centre of systems design and explore the needs and priorities of **affected persons and members of their household** to consider potential **service delivery** responses. Finally, within chapter 7, I bring these perspectives and analyses together, and draw on syndemic theory to consider how the **post conflict context in Liberia** has created a risk environment that shapes negative health outcomes in relation to NTDs and mental distress as a result of intersecting axes of inequity which are created by unequal power distribution across **multiple systems levels**, thus requiring systems-based responses.

1.5 Thesis Structure

This thesis is a publication-based thesis structured into eight chapters. In this chapter (one) I have presented the study rationale, overarching aim and objectives. Chapter two provides further background to Liberia as the study context. Chapter three presents alternative models of health, and explores the value of narrative in aligning biomedical and social understandings of health to contribute to subjective understandings of illness. Chapter three, moves on to explore the links between disease and disability before considering how social inequities shape illness experience in relation to NTDs.

Chapter four provides a detailed methodology of the study. I present the synergies between intersectional and narrative theory and detail my epistemological standpoint. This chapter was important in enabling continued reflexivity and to enhance trustworthiness of the research process, which can sometimes be limited in the 'thesis by publication' approach. Some repetition of methods is therefore present within each chapter; however, I have tried to minimise this where possible, with only methods of relevance being presented within each results chapter.

Chapter five, six and seven are all results-based chapters, presented in the form of papers. Chapter five presents findings from key informant interviews to explore how policy and programmatic reform of the NTD programme in Liberia supports systems change toward the development of people-centred health services. This paper is being prepared for submission to the International Health Journal. Chapter six uses Frank's narrative types to consider NTDs as a 'biographical disruption' and is published in the peer-reviewed literature in *PLoS NTDs* (Dean et al., 2019b). Chapter seven, the final results chapter, draws analyses of all data sources together to consider the possibility of a syndemic interaction between NTDs and mental distress in Liberia before exploring how health and social systems can respond (I have responded to comments from reviewers for publication within Social Science and Medicine).

Finally, chapter eight allows me to bring findings from all of the results chapters together to consider my contribution to the literature regarding the use of narrative

approaches for health systems reform. It also allows me to explore what strategies could be implemented by the NTD programme in Liberia and elsewhere to support person-centred responses to the management of NTDs. Limitations of the thesis are also discussed.

Chapter 2: Background to Liberia

2.1 The Pathway to Conflict

Liberia's uniquely complicated colonial past and inescapable dependence on the USA has been linked to ongoing tensions between individuals, communities and the government(Fuest, 2008, Jones et al., 2018). In 1847, descendants of freed slaves from the USA, the West Indies, and slave ships off the West African Coast, resettled to found the first African Republic. Thus, through a process of 'black colonisation'(Fuest, 2008) Liberia was born; *'a country of almost impossible social, religious and political complexity(Cooper, 2017)'.* Despite being believed never to have exceeded 6% of the native population, freed slaves – or 'congo people' or 'Americo-Liberians' as they are locally known- became the ruling classes and are described as having dominated political, social, and economic life for more than 130 years(Fuest, 2008). Various indigenous African groups rapidly became suppressed and exploited, taking on roles as labourers and household help with many treated as an underclass(Cooper, 2017, Fuest, 2008). 'Congo people', named by native Liberians due to the association of the Congo river with the slave trade, rapidly outlawed the slave trade, leaving many native Liberians without a source of revenue. To the settlers, native or indigenous groups frequently became referred to as a collective group of 'country people'. However, the social composition of 'country people' was complex and diverse, comprising of 28 different ethnic groups each with their own individual beliefs, practices and centuries old enmities. Two deeply divided societies were created, with Christianity as the only source of unification(Cooper, 2017).

In 1980, Americo-Liberian rule was overthrown by a military coup. The coup was framed as a response to an exclusionist and elitist government, economic stagnation, declining trade and weakening social infrastructure, with a vision for increased participation from an indigenous elite(Johnson-Sirleaf and Miles, 2009). Fuest (2008) describes the commencement of the Liberian conflict as founded in multiple factors, specifically:

> *'traditionally hierarchical organizations based on the control of labour and marriage, which amounted to domestic slavery for many*

> *of those considered as junior dependants, in particular male and female youths; the hegemony of the Americo-Liberians; the economic dependence on exports and international trade relations; as well as the rulers' propensity to allow the unchecked exploitation of the country's natural resources, so encouraging the predatory interests of international business'(Fuest, 2008p208)*

However, the new Afro-Liberian government failed to share power and resources, resulting in the commencement of a 14-year civil war with intense periods of conflict between 1989-1996 and 1999-2003(Nabyonga-Orem et al., 2016). The civil war resulted in the displacement of half of the 2.5 million population, and claimed the lives of between 150,000 to 200,00 people(Fuest, 2008). In 2003, a comprehensive peace agreement was signed by the warring factions, and the international community developed a shared ambition to prevent Liberia from re-entering civil war. The largest UN-Military operation to date was launched with 15,000-16,000 military and police forces and 1,500 UN civilian staff being deployed all over the country. Peace was maintained and resulted in the democratic election of Africa's first woman leader, President Ellen Johnson Sirleaf in 2005(Cooper, 2017).

2.2 Women and Peace

Women were central in the Liberian peace process and this must be recognised in the country's political and social history. The war in Liberia generated an unusual level of female collective action compared to other peace movements in other African nations. In 21st century Liberia, there is a widely recognised new spirit amongst women. Fuest (2008 p202) describes this as a *'remarkable emancipation from their pre-war positions',* with many women now able to live independently and fulfil positions of high regard within office and religious institutions. However, the extreme exploitation and hardship (both physical and psychological) experienced by Liberian women during the brutal civil conflict should not be ignored(Johnson-Sirleaf and Miles, 2009). Many women are still experiencing and enduring the enormous 'female losses' that conflict and post-conflict violence creates. However, looking beyond women as victims is also essential to be able to explore how the

disintegration of social institutions that define women's roles created opportunities for social, political and economic mobility for some women(Fuest, 2008). The social position of women for whom such mobility was enabled is critical. The sustainability of change and the ways in which Liberia's women were or are affected in diverse ways depending on their respective status, wealth, network position, and access to education is essential in understanding gender transformation in this context. High levels of gender based violence experienced during the conflict may intensify as women demand further autonomy, and gender and generational conflicts may challenge women's resistance and ambitions(Fuest, 2008). However, compared to other countries, historical and present-day conditions may facilitate profound opportunities to enhance the possibility of institutionalising female gains(Fuest, 2008).

2.3 The Road to Recovery

Despite ongoing recovery efforts, Liberia is one of the poorest countries in Africa with an average per capita income of US$160 and ranks 181/188 in the human development index (Fearon et al., 2009). The protracted conflict in Liberia left devastating impacts on the country's economy, human capacity, infrastructure and security(Nabyonga-Orem et al., 2016). At the end of the civil war, 70% of school buildings were partially or wholly destroyed, and over half of Liberian children and youth were estimated to be out of school; 'a *whole generation of Liberians had spent more time in war than in school*' (Lee et al., 2011p3). Unemployment levels were extremely high with ex-combatants, returning refugees, and internally displaced persons all struggling to find work(Lee et al., 2011).

Liberia's total debt was estimated at USD$4.9 billion which equated to 800% of GDP and 3,100% of exports(Lee et al., 2011). Between 2000 and 2005 government revenue fell to less than US$85 million per year- leading to public spending of about US$25 per person per year. The impact on the health system was also significant with only 354 (12 public hospitals, 32 public health centres, and 111 private clinics) functioning health facilities, 80% of which were managed by non-governmental organisations and faith-based providers. The total health workforce was 3, 107

persons: 168 physicians, 273 physician assistants, 443 registered nurses, and more than 1000 nurse aides, of which the majority were based in the capital city (Monrovia)(Lee et al., 2011).

The Poverty Reduction Strategy (2008-2011) was designed to support Liberia to transition into a model for post conflict recovery during the plan period. Since 2008, GDP has continued to grow within the 7-11% range(Lee et al., 2011), although recent political changes and government transition may have stalled this progress. During the immediate post conflict period there was a large reliance on humanitarian assistance to a highly fragmented health sector(Bloom et al., 2015). Under the direction of the Poverty Reduction Strategy, the 2007 National Health Policy was developed with the goal of improving the country's health and social welfare status, specifically prioritising equity in health. The National Health Policy presented a basic package of health services that prioritised decentralisation, primary health care, and focused on a limited set of entitlements including mental health (encompassing depression, epilepsy, substance abuse, and gender-based violence) and HIV/AIDS (nationwide prevalence 1.5% in 2007)(Lee et al., 2011). This also led to the creation of the health pooled fund through a joint financing agreement between the Liberian Government and its international funding partners. The purpose of the fund was to enable oversight of the Ministry of Health, support national ownership, reduce transaction costs associated with managing multiple donor projects, and to promote sector budgeting and sectoral support(Lee et al., 2011).

By 2008, health and social welfare spending had reached USD$100 million, equivalent to USD$29 per person (15% of GDP)(Lee et al., 2011). However, 47% of expenditure is attributed to external donors and 35% to households, with government contribution to spending approximately 15%. A disproportionate burden of out-of-pocket spending is placed on the poor: 64% of households are living below the poverty line, each spending roughly USD$10 per person per year on health. Furthermore, the poorest 20% are thought to spend as much as 17% of their annual income on health(Lee et al., 2011). By 2010, 80% of pre-existing and newly established health facilities met targets associated with the basic package of health services. However, significant rural-urban inequities in healthcare access remain,

with 15% of urban households and 66% of rural households not having ready access to a health facility. Prior to commencing the re-building of the health sector (predominantly health infrastructure), needs assessments were not completed due to rapid targets. This led to a lack of evidence informed planning, and an obvious lack of consideration of patient preference(Lee et al., 2011). Currently, no national formula exists for determining the level of resource allocation to counties based on population, utilisation and access criteria, and consequently disparities in healthcare access are likely to remain(Lee et al., 2011).

Health indicators in Liberia are reflective of the complex social and political history that has led to protracted conflict, fragility and health inequity. For example, in 2010, life expectancy at birth was 59.3(Lee et al., 2011). Although declining over the 15 years prior, in 2013, the infant mortality rate per 1,000 live births was 54, and the maternal mortality rate per 100,000 live births was 1,072. 45% of households have no toilet facility at all. 47% of females and 33% of males aged 6 and older have never attended school and 48% of women and 71% of men are literate (Liberian Insititute of Statistics and Geo-information Services et al., 2014).

More recently, the West African Ebola outbreak further weakened Liberia's health, economic and social infrastructure. More than 10,500 cases of Ebola were reported in Liberia (2014-2015), causing nearly 5000 deaths(Ling et al., 2017). Initial responses to the Ebola epidemic led to distrust between communities and health systems actors, due to divergent opinions on best practices or approaches to disease control. Overcoming this distrust- through adaptation of traditional approaches and collective action between the Ministry of Health, County Health Teams, community leaders, and foreign donor implementing partners-, became central to enabling Liberia to become the first country to be declared Ebola free in May 2015(Nabyonga-Orem et al., 2016). Despite this success, during the Ebola response, strengthening of permanent health system infrastructure and development of human resources was not prioritised. Consequently, lasting improvements to the health system were not observed. Priorities of community respondents for health systems reform were rarely considered in epidemic responsiveness and often differed from those co-ordinating the response. For example, communities frequently prioritised

improvements to service delivery that responded to a wide range of health concerns as opposed to systems level surveillance and co-ordination. Lack of consideration of community perspectives in intervention responses reaffirmed pre-Ebola concerns in relation to health systems development in Liberia that vertical interventions implemented in isolation may not strengthen weak health systems(Ling et al., 2017).

Post-Ebola, the Liberian Government has taken multiple steps to try to support longer term and sustainable investments in the strengthening of the Liberian Health System. The 'Investment Plan for Building a Resilient Health System in Liberia' outlines these key steps, including: the establishment of the National Institute for Health Research, investment in health workers, and the planned upgrading of health infrastructure(Ministry of Health, 2015a, Nabyonga-Orem et al., 2016). However, a critical funding gap remains with a USD$700 million gap in requested compared to committed donor aid, thus hindering the effective implementation of the plan(Ling et al., 2017). Policy dialogues have also been initiated within the health sector to support reform and strengthen policy making. Focus areas have been the development, implementation and monitoring of the health sector strategic plan; capacity strengthening, particularly focused on planning and budgeting; and operalisation of health financing. Despite varying levels of success in including a wide range of stakeholders within these policy dialogues, including those at the sub-national level, community participation is frequently lacking. Absence of community participation is described as resulting from a lack of well-established community structures coupled with no clear definition of who should be involved in the policy decision making process(Nabyonga-Orem et al., 2016).

2.4 The Journey Ahead

Aid dependency has become a central theme within Liberia's development process. However, aid and aid dependency has frequently been critiqued due to an absence of harmonisation and alignment to the country's and communities needs and priorities(Fearon et al., 2009, Nabyonga-Orem et al., 2016). Innovations such as the health pooled fund, merging of community and 'disease control expert' strategies in controlling the Ebola epidemic, and more collaborative policy dialogues that involve

sub-national stakeholders and community members are critical in health systems reform in Liberia. Such approaches require new ways of knowledge production and decision-making that challenge the business as usual model of aid delivery(Lang et al., 2012). Current movements in Global Health describe this shift in the control of funding and research agendas as the decolonisation of science or global health(Mutapi, 2019). African-led agenda setting builds sustainability within systems and processes and is an ethical imperative in responding to the ongoing inequities that existing aid and development models perpetuate(Mutapi, 2019). However, shifting the poles in global health decision making, particularly in a context of high aid dependency, is challenging. Key strategies identified within the discourse are the involvement of actors from outside academia, trans-disciplinary approaches, and community-based participatory interactions(Lang et al., 2012). Exploration of mechanisms that facilitate such approaches within Liberia need to be established to support the continued and locally owned development in relation to health and social services. As Lee et al. (2011) suggests, the answer to many of Liberia's health and social challenges will:

> *largely depend on the capacity of the international community to 'turn the world upside down' and establish common cause with Liberia, bolstering its reconstruction efforts while benefitting from new ideas and innovation (Lee et al., 2011p12).*

Neo-colonial approaches that shape the historic dominance of bio-medical top-down approaches to development aid are common within global health and often lead to community frustrations when such approaches fail to adapt to traditional systems of care(Green, 2019). There is no single solution to addressing the neo-colonial influence on health systems development, however, throughout this thesis, I try to provide critical reflection on how neo-colonial approaches may be shaping health systems reform in Liberia.

Chapter 3: Literature Review

3.1 Chapter Overview

Within this chapter I introduce key debates and literature that is relevant to this thesis. Concepts of health, illness, disease and sickness are introduced, before exploring the value of narrative in understanding illness experience and their alignment to exploration of illness. Definitions and models of disability are presented and the relevance of and approaches to the mainstreaming of disability within international development agendas explored. I conclude by exploring the current evidence base in relation to illness experience of NTDs. Given the links between NTDs, morbidity and disability, experiences of people with disabilities (often as a result of NTDs) in relation to other axes of inequity such as gender and poverty are also considered. Theoretical aspects of the core debates that are relevant to my methodological foundations are further discussed in chapter four.

Exerts within this sub-section are published within a Knowledge for Development Emerging Issues Report which I developed for DFID during the completion of this thesis. This report was requested following the presentation of my work during the 2018 Health Systems Global Conference in Liverpool. As a result, I conceptualised and drafted and finalised the report through the synthesis of existing literature (already previously completed as part of this thesis). RTol was engaged in supervision in her capacity as one of my thesis supervisors. KA was engaged in report reviews as the co-ordinator of the DFID platform through which the report was commissioned. RTh was engaged as a reviewer as the Director of the COUNTDOWN consortium to which this thesis is aligned (see section 1.1). The citation for the report is as follows:

Dean, L., Millington, K.A., Thomson, R. and Tolhurst, R (2018). Shaping Health Systems to Include People with Disabilities. K4D Emerging Issues Report. Brighton, UK: Institute of Development Studies.

Author Contributions:

LD: Conceptualisation, critical interpretive synthesis, writing first draft and editing

KA: Conceptualisation, Writing-editing

RTh: Conceptualisation, Writing-editing

RTol: Conceptualisation, supervision, writing-editing

3.2 Health, Disease, Illness and Sickness

Health, as defined by the World Health Organisation is:

> *'a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity' (Organisation, 1946).*

This definition presents a holistic view of health, as both a biomedical '*absence of disease or infirmity'*, but also comprising more social components of health, stressing the importance of *'physical, mental and social well-being*'. Holistic approaches to health and health care have, however, seldom been explored or prioritised, and there has frequently been a dichotomy in thinking in public health discourse between these approaches (Boyd, 2000). Disease, illness, and sickness, align to differing approaches to health, however all are bound in culturally embedded value-based judgements that span both biomedical and social constructs of health (Boyd, 2000).

Disease as a concept closely aligns with biomedical approaches to health and is often described as a physical process that suggests deviation from socially constructed biological norms (Boyd, 2000). Traditionally, highly medicalised definitions of disease ignore social constructs and values despite understandings of disease and their severity varying by region and country. Illness as a term is linked but not exclusive to the presence of disease, and aligns more closely to social constructs of health by taking account of subjective experiences associated with disease. Illness is inherently connected to an individual's own reality and personal experience and therefore, in theory, becomes less 'objectively' defined than a medically defined disease (Boyd, 2000). Both disease and illness are however individualistic terms located within a social context. In contrast, sickness, focuses on how illness is negotiated within society based on collective understandings or perceptions of disease(Boyd, 2000). This can present an inequity between different sicknesses: sickness based on a medical diagnosis of disease is often given much more validity than sickness which is based on illness alone. This can have significant consequences for individuals living with certain illnesses that may never attain a formal diagnosis or be associated with a specific disease. Furthermore, it negates experience of disease or illness, such as chronic pain, that may continue despite biomedical intervention to 'cure' or mitigate

against disease. This is particularly critical when thinking about illness experience and associated consequences for mental health and wellbeing. Currently, disease, illness, and sickness are thought about as distinctive categories with interactions between the conceptualisation of disease, illness and sickness seldom being explored. The interactions and synergies between concepts need to be explored to ensure holistic approaches and understandings of health and health care(Barrett, 2005).

3.2.1 Historical Perspectives of Disease and Illness: the dichotomy between the medical and the social, towards a more holistic paradigm?

Writings focused on the history of medicine place great importance on the use of narrative and feeling in diagnosis, particularly during the evolution of the doctor-patient relationship(Bury, 2001). However, with the advancement and professionalisation of biomedicine, patient experience became less critical. Under the influence of modernisation, biomedicine has prioritised treatment and cure through medical intervention with less emphasis on the importance of management and care associated with disease (Bury, 2001). In many high-income countries (HICs), there has been a recent shift back towards the importance of patient narrative within medical discourse. Bury (2001) describes the increasing prioritisation of patient narrative as linked to a decline in the prevalence of infectious disease, accompanied by a rise in degenerative and chronic illnesses. Patient narrative and experience has been cited as of critical importance for medical practitioners when considering chronic illness and planning for rehabilitation. Chronic illness often dominates the experience of everyday life, thus illness narratives once silenced by medicine have found a new voice (Bury, 2001, Pluta et al., 2015). In addition, in HICs there is increasing lay access to biomedical information regarding cause and treatment of disease, and as a result, paternalistic approaches to disease underpinned by biomedicine are challenged by illness as contextualised by the individual (Bury, 2001).

In many low- and middle-income countries (LMICs), particularly those in sub-Saharan Africa, landscapes of biomedicine and the importance of narrative are complex and varied. Biomedicine and its associated lack of prioritisation of patient narrative often

dominate public sector provision through formal governmental health systems and health interventions designed and delivered by international agencies. This is unsurprising given health systems design in such contexts has historically been based on western ideals of medicine and health as a result of historical colonial endeavours and imperial interests(Saha, 2019). This has frequently led to the exclusion of traditional systems of healing from the development of the public health sector(Tilley, 2016). However, traditional health systems remain prominent and valued in many LMICs. Given the more social underpinnings of many traditional or informal health systems, they often place greater value on the use and importance of patient narrative and illness experience in diagnosis and treatment of disease. Most commonly, appreciation of patient narrative is bound and rationalised through community understandings of cause and origin of sickness(Tilley, 2016).

3.2.2 Constructs of subjective experience of illness through the use of narrative

Personal narratives are often used as a way to understand the experience of individuals and interpret how they link their body, self and society (Bury, 2001). They aim to reduce the suppression of narrative and fracturing of accounts that can occur with many forms of interviewing. Specifically, the highly open nature of the process aims to reduce the atomisation of content of experience by placing the prioritisation of events within the control of the individual (Bury, 2001). Kleinman and Seeman (2000)stress the importance of narrative as a way to bear 'witness' to the 'suffering' of those living with a chronic illness. Personal illness narratives take many forms and serve many purposes. Often such narratives are described as providing voice to the 'weak' patient in the face of domineering medicine or as a way for individuals to construct a changing identity following illness diagnosis (Bury, 2001, Pluta et al., 2015). However, it is critical to understand that illness narrative is always an edited version of an individual's reality based on what they choose to share within a particular interaction and context, and thus knowledge becomes a co-construction between the individual and the person to which they are telling their narrative (Bury, 2001). Furthermore, linking self, body, and society often relies on an interpretive act of the researcher or reader who has to reflect on the gaps between experiences and

communication about it (Riessman, 1993). Interpretations of illness narrative often present pain as a chief metaphor, pain as both physical and social, and the emotional pain of loss (Barrett, 2005).

Narrative analysis frequently draws on narrative 'type' as a mechanism through which to draw closer attention to the stories of the person who is 'ill'(Frank, 2013). Most typically, narrative types are identified to support the recognition of the underlying plot and tensions within particular stories (Bury, 2001, Frank, 2013, Riessman, 1993). One risk with the use of narrative types is the impression that there is one unifying view of illness experience. However, narrative types are not mutually exclusive, rather they may describe different emphases of the individual at different points in the life course in relation to health (Bury, 2001). Analysis of narrative accounts should be mindful of this and see 'types' of narrative as a useful tool through which to understand complex and interwoven narrative threads that enable people to recount their own realities (Bury, 2001, Frank, 2013, Riessman, 1993). As Frank (2013) describes, narrative types:

> *'are like patterns in a kaleidoscope: for a moment, different colours are given one specific form, and then the tube shifts and another form emerges'(Frank, 2013p76).*

Typically, various narrative types could be associated with having underpinnings linked to both biomedical and social understandings of health and consequently constructs of disease, illness, and sickness. This is further described in section 6.5.1. Debates in approaches to narrative analysis and the way in which I approach narrative analysis within this thesis are further explored within Chapter four (sections 4.2.1, 4.2.2 and 4.2.4).

3.3 Health and the Household

Analysis that considers the household production of health (HHPH) recognises the central role of households in how health is produced, promoted, maintained and protected within the household (Agbo et al., 2019, Berman et al., 1994). Households from this perspective become less defined by structure or cohabitation, rather, they

become defined by functional criteria or routine participation in decisions that affect health and wellbeing. Consequently, households may include kin (both proximal and distant) who contribute to the household in some way, and derive part of their identity by association with the household (Agbo et al., 2019). Roles and relations within households become central to the HHPH. However, relations within households may be '*competitive and co-operative'* at different times depending on characteristics that shape individual identity and position within household hierarchies such as age, gender, marital status and financial contribution(Agbo et al., 2019). For example, in relation to gender, despite both productive and reproductive work being essential in the production of health, the value of reproductive work is often unrecognised (Folbre, 1986). Recognition of the value of reproductive roles in the production of health is essential in the development of people centred health systems as it is often these individual, household and community interactions and norms that become the central drivers in the production of health (Chapter 1, Figure 1).

Sen (1990) theory of intra-household bargaining suggests that different members of the household have different decision-making powers that influence access and allocation to resources. Bargaining positions become shaped by the interaction of inequities associated with for example, gender, age, wealth and education. At the household level, this can cause differing vulnerabilities and resilience to disease, illness or sickness at three different levels. Firstly, access to treatment and care often involves negotiation over household resources, particularly where household resources are limited. Individuals with a greater degree of power within the household, usually men or older women, such as a mother in law, tend to have increased decision or negotiating power over resources and consequently may have better health outcomes. Increasing equity within the household has been shown to improve health status of the entire household due to more equitable decision making and resource allocation (Richards et al., 2013). Secondly, ill health can often influence the household in relation to economics- productivity often becomes reduced. There are direct costs associated with seeking care; indirect costs associated with members of the household taking on the role of a caregiver; and opportunity costs when both

patients and caregivers are no longer able to provide economic income to the household. Such economic losses can exacerbate or induce poverty, which in turn has negative implications on household health. Finally, when considering the household and health, lifecycle approaches need to be considered (Tolhurst et al., 2016). Poverty as a result of ill health and vice versa often have generational impacts that extend beyond the immediate household. In developing health interventions interruption of cycles of poverty and ill health therefore need to be considered. In addition, the critical importance of household dynamics on health outcome should be given focus, in particular the influence of changes in household structure due to conflict, disease and social change should be reflected upon with particular emphasis on its influence on household inequities.

3.4 Disability and Disease in the Global Context

The majority of research related to disability in LMICs has taken place in the last decade(Mitra, 2017). Disability in LMICs is not rare and is frequently associated with other axes of social disadvantage such as poor educational attainment, lower employment, and limited access to health care. Disability is also associated with experiencing simultaneous and multiple deprivations (see section 3.6)(Mitra, 2017, World Health Organization, 2011b). However, despite increasing global recognition (for example within the SDGs), the conceptual definition of disability is elusive and constantly evolving. Better understandings of disability are needed to enable its study and measurement to inform policy and programming, and to allow for cross-contextual comparisons(Mitra, 2017). This is particularly important in LMICs where the advancement of disability studies has lagged, due to the common mis-conception that disability is an issue that has greater relevance in high-income settings, as a consequence of ageing populations and better life expectancy irrespective of injury or experience of health conditions(Mitra, 2017). In the following sub-sections, I explore existing definitions and constructs of disability and situate these understandings within capacity and development theory to inform the rational for my approach to disability within this thesis as described in section 4.2.5.

3.4.1 (World Health Organization, 2011b)Defining Disability

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) reflects characteristics of disability in their definition which states;

> '*Persons with disabilities include those who have long-term physical, mental, intellectual, or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others'(United Nations General Assembly, 2007p3).*

However, disability is often thought of as an evolving concept and one without a single or universal definition (Rohwerder, 2015b). Similarly, to health and gender, multiple models of disability exist that are all likely to inform discussions or analysis of disability in some way regardless of how this is explicitly or implicitly acknowledged in study design(Mitra, 2017). Like all models, models of disability (and the components of different models that we adopt), shape the way in which we describe and understand the concept, including its determinants, consequences and the responses that we promote. Contestations are ongoing in relation to the 'best' approaches to understanding disability and it has been argued that approaches to disability studies are frequently determined by interactional processes studied in high income settings (Mitra, 2017) (Anand, 2016). Models of disability fit into two broad realms; the medical or individual and the social (Al Ju'beh, 2015, Rohwerder, 2015b, Ghai, 2001).

3.4.1.1 *The Medical or Individual Model*

Medical models of disability focus on an impairment that needs fixing as a result of disease, injury or illness. People are deemed disabled based on their ability to function 'normally' within society, restricting disability to an individual phenomenon (Mitra, 2017, Rohwerder, 2015a). Medical models have been criticised for lacking consideration and exploration of barriers that are often imposed on individuals as a result of the environment or society (Rohwerder, 2015b). Interventions, policy and programmes that adopt a medical model of disability tend to focus on the provision of rehabilitation and healthcare, which can lead to paternalism and pathologisation

(Goodley, 2016). Charity models of disability also take an individualistic approach to disability, in which individuals are pitied as passive victims and tend to be identified by their impairment (Al Ju'beh, 2015).

3.4.1.2 *The Social Model*

Social model(s) of disability were developed to take a broader, more societal view of disability and see disability as a construction of society in which an impairment is located (Mitra, 2006a, Woodburn, 2013). Social models of disability focus on transformation of unjust systems in which the participation of people with disabilities are central (Addlakha, 2013, Al Ju'beh, 2015, Rohwerder, 2015b). Impairment tends to refer to an individuals' condition, whereas disability is specifically connected to the social disadvantage, discrimination and exclusion that individuals face as a result of their impairment (Mitra, 2017).

The definition presented above aligns to a rights-based approach to disability which originates from the social model. Rights based models of disability have gathered momentum with the increasing presence of disability rights movements over the last decade, particularly given the introduction of the UNCRPD, and are growing in usage within academic discourse. Despite being constructed in relation to situations within high income countries, social models of disability and rights-based approaches have also gained increasing traction within LMICs and often becomes a framework that spans the intersection of disability and development (Mitra, 2017).

3.4.1.3 *Interactional Models*

Most recent approaches to disability within policy and planning recognise the importance of understanding disability neither as a purely medical or purely social phenomenon; such models are known as interactional models (Rohwerder, 2015b). Interactional models of disability focus on people living with disabilities experiencing problems as a result of the interaction between a health condition and the environment. The most common interactional model is the international classification of functioning, disability and health (ICF), which focuses on the interaction of health conditions and the context in which they are located (World Health Organization, 2011a). In this model, within a specific context a health condition (disorder or disease) can lead to impairments (problem in bodily function),

activity limitations (completion of a task by an individual) and or participation (involvement in a life situation) restrictions. Contextual factors consider individual identity-based characteristics such as age, gender, education, as well as structural factors such as the physical environment, social attitudes, laws, policies etc, which may become barriers or enables when it comes to individual functioning. Functioning becomes the direct opposite of disability and disability becomes an overarching term for impairments, activity limitations and participation restrictions(World Health Organization, 2011b).

Despite gaining considerable influence internationally, the ICF is sometimes criticised as it is suggested that it doesn't significantly reflect the discrimination experienced by people living with disabilities(Groce et al., 2011). As a result, the capability approach is also often used as an interactional model because it has been argued that it reflects in greater detail individuals' lack of capability to participate based on individual characteristics, resources and the environment (Mitra, 2006a).

3.4.1.4 *The Capability Approach and Disability*

The capability approach is not unique to disability studies and has been applied across a range of disciplines to tackle issues related to human development including poverty and social justice(Mitra, 2017, Mitra, 2006b). The capability approach, originally conceptualised by Amartya Sen, focuses on the life that individuals are able to live based on: 1) practical opportunities (*capabilities*) and 2) achievements (*functionings*) (Sen, 2014). In disability scholarship, the capability approach has been applied to consider: how to respond to justice demands(Nussbaum, 2009); to evaluate the philosophical groundings of human rights(Venkatapuram, 2013); to consider inclusivity of education; and to compare wellbeing across disability status (Mitra et al., 2013). Sen's approach has allowed consideration of the extent to which the nature of specific deprivations are experienced by people with disabilities and how this influences their comparative wellbeing (Mitra, 2017).

Disability becomes defined by a functioning or capability deprivation in general, i.e. an impairment becomes a feature of an individual that may or may not lead to disability depending on its impact on capabilities and functioning. However, deprivations are thought to be shaped by *conversion factors* which are defined by an

individuals' ability to convert resources into *capabilities* and *functioning*. *Conversion factors* are influenced by multiple components that influence individual circumstance including personal factors and the broader social and structural environment (Mitra, 2017). Thus, by combining this approach to disability with intersectional thought, the influence of intersecting axes of oppression on the nature of deprivation can be considered. This allows for the creation of policies and suggested reform to address social and structural inequities that could promote the enhancement of social justice and human development for persons with disabilities. My approach to disability within this thesis is further discussed in Chapter 4 (4.2.5).

3.4.2 Disability and Disease: What are the links?

Disability can pose a challenge to the "absence of disease or infirmity" clause within definitions of health, as many people with disability still aspire to and have a right to "health" within the limitations of their impairment or activity limitation. People living with a disability may or may not experience acute or chronic illness; rather like all individuals, they have their own specific health needs which are diverse depending on subjective experience. Chronic morbidity and disability dominate the experience of everyday life, so understanding how individuals conceptualise and navigate these experiences in relation to their health and wellbeing becomes critical to be able to respond in appropriate ways (Bury, 1982, Pluta et al., 2015).

Disability, disease, and ill-health are connected through multiple, multi-directional pathways, which are discussed in turn in this sub-section. Specifically, individuals living with disability, particularly those based in LMICs, face greater challenges in accessing health and healthcare services and as a result are thought to have poorer health outcomes (World Health Organization, 2011a); and both communicable and non-communicable disease can lead to life altering morbidity and disability, particularly in contexts where health infrastructure is weak. For people with disability, exclusion in relation to healthcare often limits the attainment of full health potential and spans several key areas including: challenges in accessing health facilities; poor quality of care associated with disability when reaching a facility; lack of inclusion or adequate adaptation of public health campaigns; and a lack of access to nutrition, water and sanitation services, which can exacerbate impairment (World

Health Organization, 2011a). Likewise, people with disability are often at greater risk of being affected by communicable disease due to the complex relationship between disease, disability and poverty.

Thus, health systems have a dual role in the management and treatment of both communicable and non-communicable disease. They need to be able to: 1. Address the needs and rights of people with disabilities as a population group at heightened risk of communicable and non-communicable disease as well as at risk of exclusion from services. 2. Address communicable and non-communicable diseases as leading causes of disability. This thesis discusses necessary health system responses in relation to chronic disease, morbidity and disability as a result of preventable communicable infection as a case study to support the mainstreaming of disability within health systems thinking.

3.4.2.1 Communicable Disease and Disability

Communicable diseases such as TB, HIV, malaria and many NTDs, including lymphatic filariasis, onchocerciasis, leprosy, and Buruli ulcer can lead to chronic morbidity and disability. For example, the latest estimates of the burden of disease in terms of disability-adjusted life years (DALYs[6]) lost due to illness and death are 58 million for HIV/AIDS, 56 million for malaria and 44 million for TB in 2016 (Global Health Data Exchange, No Date). Additionally, chronic effects of lymphatic filariasis are described as the second leading cause of physical disability, with 40 million people thought to be affected worldwide. Finally, in combination, severe stigmatising skin diseases (including the diseases of focus within this thesis), are thought to be the 4th leading cause of disability globally (Williams and Kovarik, 2018).

Despite clear links between communicable disease, chronic impairment and disability, disease control efforts in relation to these diseases are frequently implemented through vertical disease programmes that are aimed at interruption of

[6] DALYs are used here to illustrate the links between communicable disease and disability. However, in using this measurement I also appreciate associated critiques and limitations. Specifically, that the use of DALYs can presuppose that the lives of people with disabilities have less value than people without disabilities, and can assume that people with disabilities should have less access to scarce health resources that may support to extend their lives. (ARNESEN, T. & NORD, E. 1999. The value of DALY life: problems with ethics and validity of disability adjusted life years. *BMJ,* 319**,** 1423-1425.)

disease transmission or “curing” infection. These approaches are important, but do not consider the fact that many communicable diseases may still cause lifelong morbidity and/or disability, even with successful treatment of the infection, as is the case in relation to NTDs and discussed within section 1.2.1. This requires consideration of the chronicity of these conditions in health systems strengthening efforts and demands for the development of more “horizontal” health interventions.

3.4.2.2 Non-Communicable Disease and Disability

LMICs also have a large and growing NCD burden(Richards et al., 2016) exacerbated by ageing populations(Kämpfen et al., 2018). NCDs, including diabetes, cardiovascular disease and chronic lung health conditions such as COPD, are thought to contribute to approximately 80% of years lost to disability, and people with disability are thought to be at increased risk to NCDs(Richards et al., 2016). NCDs can lead to impairments related to amputations, blindness, mobility and speech. Such impairments can reduce productivity, increase demand on the social and health systems and impoverish families due to associated activity and participation restrictions. It is estimated that between 2008 and 2030, diabetes, cardiovascular diseases, cancer, chronic respiratory diseases and mental illnesses will cost LMICs US$21 trillion due to illness and lost production(Kruk et al., 2015).

Information on the prevalence of NCD-related disability and corresponding rehabilitation is scarce(Richards et al., 2016). For many LMICs, the Global Burden of Disease study estimates of disability-adjusted life years (DALYs) and years lost to disability (YLDs) are all that is available. The latest 2016 estimates of the burden of disease in terms of DALYs lost due to illness and death are 57 million for diabetes, 353 million for cardiovascular diseases and 163 million for mental disorders. Seventy percent of people with diabetes live in LMICs(Richards et al., 2016). The primary goals of NCD care – to enhance functional status, minimise symptoms and prolong and enhance quality of life, rather than to cure – are not captured in current health information systems(Richards et al., 2016). Local valid data on rates of NCD-related disability, statistics on functional status, rehabilitation needs, and the coverage and utilisation of relevant health services are required to measure disease burden,

evaluate the effectiveness of health interventions and build the evidence required to guide policy responses(Richards et al., 2016). Richards et al. (2016)argue for the need to improve health data by: incorporating measures of NCD-related disability into discussions on NCD prevention and control; strengthening information systems to better capture data on disability; and aligning NCD and disability measurement and monitoring strategies. They also argue for the chronic disabling states caused by NCDs to be recognised and incorporated in all global action and monitoring frameworks on NCD prevention, control and treatment.

The link between NCDs and chronic ill-health also needs to be considered in health systems responses to disease and disability. This is particularly important in relation to mental health conditions, which are anticipated to be the largest contributor to the global health burden by 2030(Litt et al., 2012). Exploring how to support health systems to respond to chronic morbidity as a result of NTDs is also likely to support in shaping the development of health systems that are responsive to changing NCD burdens.

3.5 Disability and Development

Disability is referenced in various parts of the SDGs and specifically under five of the seventeen goals – goal 4 guaranteeing equal and accessible education by building inclusive learning environments and providing the needed assistance for persons with disabilities (PWDs); goal 8 promoting inclusive economic growth, full and productive employment allowing PWDs to fully access the job market; goal 10 emphasising the social, economic and political inclusion of PWDs; goal 11 creating accessible cities and water resources, affordable, accessible and sustainable transport systems, providing universal access to safe, inclusive, accessible and green public spaces; and goal 17 underlining the importance of data collection and monitoring of the SDGs, with emphasis on disability disaggregated data. As well as specific references within the SDGs to disability, the underlying principle of the SDGs of “leaving no one behind” emphasises the inclusivity of all the goals, ultimately rendering them relevant and disability mainstreaming critical in their attainment(United Nations, No Date).

3.5.1 The United Nations Convention on the Rights of Persons with Disabilities

The Convention on the Rights of Persons with Disabilities (CRPD) and its Optional Protocol was adopted on 13 December 2006 at the United Nations Headquarters in New York and entered into force on 3 May 2008. The CPRD has been the most rapidly ratified international treaty - as of 11 November 2016, 168 States and the EU ratified the Convention, representing 87% of Member States in the United Nations. The World Health Organization (WHO) and World Bank Group subsequently jointly produced the World Report on Disability in 2011 to provide the evidence for innovative policies and programmes that can improve the lives of people with disabilities and facilitate the implementation of the CRPDs(World Health Organization, 2011a). The CRPD emphasises the right to health and rehabilitation with two specific requirements of ratified states:

- To ensure that persons with disabilities are reasonably accommodated in the context of health care services, and
- To ensure accessibility more generally to health care services.

3.5.2 Approaches to Inclusion

Many approaches to disability inclusion have been established and put into practice. Principally they include:

- mainstreaming, which involves thinking about disability in all aspects of development;
- twin-track approaches, which in addition to mainstreaming focus on disability specific interventions;
- reasonable accommodation to encourage necessary and appropriate modification to environmental, communication and service delivery, to ensure people living with disability can exercise their rights on the same basis as others;

- and community-based rehabilitation which prioritises the rehabilitation, poverty reduction and social inclusion of people living with disabilities.

Having said this, there still remains a lack of evidence for the success of such interventions, as the majority of research into disability focuses on identifying or exploring exclusion, with limited reflection on what works for inclusion(Rohwerder, 2015b). In addition, although there is increasing evidence that identifies associations between disability, poverty and inequity, the nature of such relationships still needs further exploration particularly through the lens of intersectionality with reflection on what this means for disability inclusive interventions. Essentially, there is a need to move from descriptive studies to those that focus towards implementation research(Rohwerder, 2015b).

3.6 Intersectionality, Illness Experience and NTDs

There are increasing numbers of studies that explore experience of individuals affected by NTDs; however, few explore multiple axes of oppression simultaneously. Where varying axes of oppression or social phenomenon are considered they tend to be in relation to one principal factor such as gender or stigma, normally at preference of the researcher/s, with limited consideration of how inequalities or inequities may interact with each other and with social processes to cause both medical and social co-morbidities. Furthermore, social inequities tend to be considered in relation to their influence on health determinants and access to treatment, as opposed to their influence on illness experience (Manderson et al., 2009). Where social inequities are considered in relation to disease outcome, this tends to be from a biomedical standpoint in terms of risk, with limited exploration of the social conditions that may lead to such biomedical consequences (Allotey and Gyapong, 2005).

This thesis is specifically concerned with how intersecting axes of inequity shape illness experience in relation to NTDs. However, whilst conducting this study, I also completed intersectional analysis of equity within PCT interventions drawing on qualitative data from the four COUNTDOWN countries: Cameroon, Ghana, Liberia and Nigeria. To my knowledge, this is one of the only studies to utilise intersectional

theory to analyse PCT programme access within sub-Saharan Africa[7]. The study infused intersectional analysis and the Tanahashi Framework(Tanahashi, 1978) to explore inequities in coverage across multiple domains: Availability, Accessibility, Acceptability, Contact and Effective Coverage. A summary of the key findings are presented in Box 2.

[7] This paper is not included in full as part of this thesis as it draws on data from multiple COUNTDOWN countries and methods which were not included as part of this thesis.

Box 2:Exert of key findings from Dean et al., (2019) regarding how intersecting axes of inequity shape PCT coverage across the multiple domains of the Tanahashi Framework

- **Availability coverage** can be compromised due to: medicine shortages and delays because of poor requisition estimates and weak supply chain, leading to key populations being missed based on ethnicity (e.g. migrant groups) or religion; policy or programmatic engagement can mean out-of-school children or children in religious schools are missed, showing interlinkages between programme and education structures; and out of pocket payments for frontline health providers can render MDA impoverishing for those delivering drugs within communities.
- **Accessibility coverage** is hindered by the interconnection of geography, economic factors and unadaptable health systems both in urban and rural settings which can lead to context specific inequities: men were frequently left out of distribution due to condensed distribution periods and absenteeism from communities based on livelihood or economic activities; seasonality of distribution meant that some entire communities, in the most isolated settings, were excluded from distribution, showing an interaction between restrictions to programme adaptability, geography and economic factors; and limited flexibility in distribution strategies can restrict access to interventions for people living with disability, women, and men, as well as those living in urban areas.
- **Acceptability of medicines** is frequently influenced by: restrictions to autonomous decision making based on gender, age, and religion; socio-economic context (i.e. wealth and poverty) and availability of food can influence the experience of side effects and thus interconnects to shape programme acceptance; and traditional belief systems that are not considered in programme design e.g. the use of sticks for measurement can shape the acceptability of the intervention.
- **Contact coverage** is frequently impacted by patriarchal decision-making structures which determine who are CDDs as well as who CDDs can interact with. This can result in many women being untreated, or unrecognised by the programme.
- **Effective coverage** is negatively influenced when pregnant women, people with disabilities, and the chronically sick are frequently left out of programme delivery due to programmatic campaign structures and definitions of 'ill health'.

As a result of a scarcity in the literature that explores how axes of inequity intersect to shape illness experience, the subsequent sub-sections explore the broader literature base in relation to NTDs and key concepts such as gender, poverty, stigma and mental health in isolation. Thematic areas presented here were selected due to their relative dominance within existing literature (e.g. poverty and stigma), as well

as those that appeared most relevant to Liberia's socio-political context (e.g. conflict and fragility). Due to the links between communicable disease including onchocerciasis, leprosy, Buruli ulcer, hydrocele and lymphoedema (previously described in sections 1.2.1 and 3.4.1.1), within the following sub-sections, I also describe the current evidence base in relation to specific axes of oppression and NTDs as well as disability more broadly.

3.6.1 Poverty, NTDs and Disability

The NTD-poverty relationship is mutually reinforcing as poor material circumstances also place individuals, households and communities at increased risk of NTDs, due to poor water and sanitation infrastructure and extreme environmental conditions. NTDs are commonly referred to as diseases of poverty and the tight inter-relationship between poverty and inequity is well recognised. The interactions between poverty and NTDs should be considered at multiple levels; individual, household, community and country. For individuals, households and communities, the impoverishing impacts of NTDs result from direct costs linked to diagnosis and treatment, and indirect costs as a result of lost productivity, missed education, and caregiving responsibilities (Manderson et al., 2009). For example, in Ghana and Nigeria, for families affected by NTDs including Buruli ulcer, out-of-pocket spending for treatment has been observed to result in catastrophic health expenditure(Ackumey et al., 2012, Bangert et al., 2017). Furthermore, many impoverished at risk populations, particularly the geographically isolated, are frequently unable to reach preventive services(Manderson et al., 2009). Countries where NTD burden is the greatest are also frequently too poor to provide infrastructure and human resources to tackle the diseases as a consequence of crippling international debt and economic disadvantage(Manderson et al., 2009). This is exacerbated further in affected nations as associated morbidity can result in high levels of lost economic productivity. For example, in India, morbidity associated with lymphatic filariasis is thought to result in US$ 1 billion of economic losses(Aagaard-Hansen and Chaignat, 2010).

A recent systematic review indicates strong evidence for the links between disability and economic poverty, which remains true when adjusted for confounders including age and gender. This relationship was described as increasing with levels of poverty

and severity of disability. Disparities in poverty between people with disabilities and people without disability was shown to be greater in areas where wealth was generally higher, suggesting that inequities develop over time – however, understanding which factor comes first (disability or economic poverty) is still challenging(Banks et al., 2017). Thus, cumulative exposure to poverty, where many adults have been exposed to adverse economic and health environments, and the co-existence of communicable and NCD burdens in resource constrained health systems, is challenging to respond to in LMICs (Kämpfen et al., 2018). Amongst the studies included in the systematic review, where associations were not found between economic poverty and disability, other layers of analysis highlighted associations between disability and other indicators of poverty, such as educational level or employment status. Economic poverty associated with disability and NTDs has implications at the individual and household level, and can result from: direct costs associated with having to pay for increased medical and travel costs; indirect costs due to family or community members acting as caregivers for people with disability; and opportunity costs because of lost income or productive work of key members within the household(Rohwerder, 2015b).

Poverty also increases the likelihood of disability due to enhanced risk of stress and social exclusion, lack of access to healthcare, inadequate water and sanitation, malnutrition and poor living conditions, all of which can lead to poor physical and mental health that can become disabling. Simultaneously, disability often leads to exclusion from work, education and healthcare which can in turn result in, or deepen, poverty. Poverty associated with disability has been identified as exacerbated by environmental factors, gender, age, type of disability, and economic context of the individual or family prior to impairment(Rohwerder, 2015b). Despite these commonly described associations, the evidence base of the links between the broader dimensions of poverty (including social exclusion, dignity, respect, employment, knowledge/information, etc.) beyond economic poverty and disability is thin(Banks et al., 2017, Groce et al., 2011), especially when considering empirical evidence that may be used to inform the design and delivery of policy and programmes. This is perhaps due to complicated definitions of poverty and disability,

used in multiple ways by different authors, but highlights a clear evidence gap in ensuring progress toward the attainment of the SDGs and ensuring that no one is left behind(Banks et al., 2017, Groce et al., 2011). This emphasises the need for studies that explore links between poverty and disability using multi-dimensional approaches.

3.6.2 Gender, NTDs, Violence and Disability

The specific intersection between gender and disability in many LMIC settings significantly shapes disease experience, with vulnerabilities and discrimination being centred on the ability to fulfil stereotypical or socially assigned gendered roles, such as men being economic providers and women/girls as responsible for reproductive work, including caregiving. Caregiving responsibilities for people with disabilities frequently have the most impact on women and girls due to their ascribed gender roles(Zuurmond et al., 2016). Misconceptions can leave many women with disabilities unable to attain their sexual and reproductive rights as they are characterised as having no sexual needs, desires or agency(Dean et al., 2017). Men with disability are more likely to be perceived as entitled to a sexual life due to the intersection of disability and patriarchy(Addlakha, 2007). However, for many men with disability, feeling or being unable to fulfil a role as an economic provider within the household can be “emasculating” and have negative connotations for men’s mental health and wellbeing.

There is also evidence that women, men, boys and girls with disabilities face increased rates of violence, including gender-based and disability-violence, which may intersect(Fulu et al., 2014). Both gender- and disability-based violence stem from power imbalances between genders and people with or without disability(Fulu et al., 2014). Disability-based violence tends to originate in contexts where people with disabilities are not viewed as people deserving of equal rights(Fulu et al., 2014). Gender- and disability-based violence can be physical, psychological or economic, and although both men and women can experience violence of this nature, evidence suggests that, worldwide, women are more likely to experience violence and more severe violence, and for longer time periods(Fulu et al., 2014). Higher levels of violence amongst people with disabilities, particularly women, are influenced by

broader social structures, including patriarchal attitudes and social structures, relative lack of power, and limited access to services(Fulu et al., 2014).

Experiences of disability and gender-based violence in relation to NTDs are infrequently explored outside relationships to stigma (see section 3.6.3). However, a recent study that explored experiences of intimate-partner violence (IPV) amongst Ethiopian women affected by podoconiosis (lymphoedema), found that IPV was often triggered by inability to complete household chores and influenced disease outcomes in a two-way relationship. Episodes of IPV frequently included restrictions to resource access (e.g. water and healthcare), which limited women's ability to complete self-washing or disease management, resulting in increased disease severity, limited social networks, and reduced ability to complete household activities, thus further triggering episodes of IPV(Tsegay et al., 2018). A study in Nepal also described episodes of IPV amongst women affected by leprosy, identifying that five out of ten leprosy affected women had experienced sexual violence by their husbands. This was described as more likely where women were living with an alcoholic partner(van't Noordende et al., 2016). Consequently, as also suggested by Tsegay et al. (2018), within NTD programming, there is a need to improve access to IPV prevention and management services.

Women and girls with disabilities are at three times greater risk of rape by a stranger or acquaintance than their non-disabled peers, according to existing evidence(Ghai, 2001). These risks are exacerbated when poor sanitation infrastructure means women and girls must defecate openly; or when travelling long distances to school or work. This highlights a clear intersection between gender and community-level poverty, which can interact to produce vulnerability. Women and girls can be at risk in these environments due to a social and infrastructural environment that not only makes them vulnerable to sexual violence, but also presents challenges in communicating or reporting incidents of violence. There may also be risks of violence, including sexual violence, for men and boys with disabilities, particularly in conflict and post-conflict settings; however, these are even less documented and due to increased social stigma attributed to men who experience such events, reporting of incidents of sexual violence is even less likely. Barriers also exist to supporting men

and women who have experienced either gender or disability-based violence; for example, in Northern Uganda many women described having to pay fees to register incidents of sexual violence(Andrae, No Date). Thus, in the Uganda case, gender and poverty can intersect to compound vulnerabilities. Women with disabilities also often experience psychological violence, which can include wilful neglect, persistent insults, and in some cases isolation or detainment. Such experiences throughout the life course can contribute to the invisibility of disabled women, resulting in negative mental health outcomes(Andrae, No Date).

Isolation and detainment can also extend to the denial of access to healthcare, education and financial resources, all of which are often entangled with forms of economic violence and reduce the autonomy and participation of women with disabilities in decision-making processes. The evidence base on how to prevent and respond to violence in relation to people with disability is limited(Mikton et al., 2014). There is some indication that increasing the economic independence of women with disabilities is likely to decrease the risk of gender-based violence, however more work is needed in this area(Fulu et al., 2014).

Gendered analysis of NTD outcomes for individuals, although limited, tends to focus on disease outcomes predominantly for women, with limited exploration of illness experience of men and people of other genders (Rilkoff et al., 2013, Manderson et al., 2009). Specifically, as within disability literature, it tends to relate to the ability of women to be able to fulfil their stereotypical gendered role as a child-bearing wife and mother. For many women living with physical impairment as a result of lymphatic filariasis, onchocerciasis or Buruli ulcer, marriage prospects are seen to diminish due to stigmatisation linked to disease and disability. In addition, where women are already married prior to their disability they are often vulnerable to divorce, or in the case of polygamous households, their position and power within the household weakens(Allotey and Gyapong, 2005). Despite some reflections on the impact of some NTDs on health outcomes for women, little research has explored how this influences their quality of life and experience through time. It is therefore difficult to fully understand the negative psychological and social manifestations of NTDs and how this is shaped by gender. This is of critical importance when considering

hypothesised co-morbidities between mental health and NTDs, as constructions of mental health often vary significantly between men and women(World Health Organization, 2007).

Explorations of interactions between gender and other social determinants are more common in analyses of vulnerability to specific NTDs. Gender differentials in disease prevalence is often identified based on risk factors associated with gendered occupational roles, divisions of labour and everyday practices within the household, which intersect with environmental risks to shape disease exposure in different ways across diverse contexts and regions(United Nations Development Programme, 2019). For example, in fishing and farming communities' men often report higher rates of Schistosomiasis than women, whereas in communities where women wash utensils and clothes in snail infected waters they may have the same rates or higher rates of Schistosomiasis than men(Allotey and Gyapong, 2005). Men also experience higher rates of lymphatic filariasis in fishing and farming communities when they sleep outside without a mosquito net whilst working(Chesnais et al., 2014). However, in rural India, where both men and women engage in similar agricultural practices, rates of lymphatic filariasis infection are almost equal(United Nations Development Programme, 2019, Upadhyayula et al., 2012). Gendered norms linked to dress also shape disease risk. For example, in Cameroon, men and boys generally complete work or play in water with exposed bodies, increasing their vulnerability to black fly bites and consequential onchocerciasis infection. Women on the other hand often tend to be more covered due to cultural and religious norms, proving to be a protective factor in some areas(Campbell et al., 2016, United Nations Development Programme, 2019, Wanji et al., 2015). In relation to Leprosy, a recent systematic review identified that men are more likely than women to present with *multibacillary* leprosy (more than five skin lesions) and present with Grade II disabilities, whereas women are more likely to present with *paucibacillary* disease (one to five skin lesions) than men, emphasising difference in treatment seeking and delayed disease presentation based on gender. However, the review also identified that it was common for women to not adhere to full treatment regimens, sometimes due to clinic hours conflicting with domestic or household responsibilities and resulting in

physical disfigurement and impairment. Thus, long-term impact of leprosy is shaped by social factors that guide treatment adherence processes as well as stage and grading of disease at diagnosis(Van Elteren, 2017).

Gender analysis linked to NTDs has also particularly considered gendered dynamics in relation to health and treatment seeking behaviours of individuals. In relation to PCT interventions, gendered analysis has predominantly focused on attitudes and barriers toward the uptake of drugs. Challenges in drug delivery for pregnant women are a key barrier. Preventive medicines used to treat lymphatic filariasis and onchocerciasis cannot safely be administered during pregnancy(McDonald, 2011). Furthermore, despite the fact that Praziquantel (used to treat schistosomiasis) was deemed safe for administration in pregnancy in 2002, it is infrequently administered to pregnant women due to safety concerns(Organization, 2003). Given that women living in areas endemic for NTDs may spend up to 25% of their reproductive years pregnant and another 60% lactating(Rilkoff et al., 2013), this presents them at significantly higher risk of living with long term untreated NTD infections(United Nations Development Programme, 2019).

In addition, there is consideration given to the gendered interactions between young female drug distributors with older men in communities; it has been found in some studies that older men are less likely to take drugs when they are provided by young female drug distributors than if they were delivered by men or older women(Rilkoff et al., 2013). Rilkoff et al. (2013) also present findings that when men are absent from the household, for example when working outside the community, this can have a positive impact on the uptake of drugs for the rest of the household. When men who often function as key decision makers in the household are absent, women have a higher level of autonomy in deciding whether or not to take the drug.

Intra-household decision making and the influence of gender has also been seen as critical in health seeking behaviour for treatment related to NTDs. In some contexts, due to a lack of autonomy of women in relation to decision making and financial resources, as well as a sense of gendered responsibility to fulfil household responsibilities and caring roles, women often delay in treatment seeking, which can increase severity of condition or impairment(Barrett, 2005, Agbo et al., 2019). For

instance, in Kaduna State Nigeria, one study found that women often have to gain permission to seek care and as a result had more severe disease outcomes(Allotey and Gyapong, 2005). Perception of origin of condition also influences treatment seeking for both men and women in relation to NTDs in differing ways in differing contexts. For example, in India, there is a perception that Lymphatic Filariasis is hereditary in women and is therefore not recognised as a condition that can be treated clinically, causing a delay in presentation at health facilities(Bandyopadhyay, 1996). In Ghana, the same hereditary assumptions exist but in this context in relation to men (Gyapong et al., 2000).

3.6.3 Stigma, NTDs and Disability

Stigma associated with disease experience has been described as a result of lesions of onchocercal skin disease, Buruli ulcer, hematuria in urinary schistosomiasis, lymphoedema, hydrocele and leprosy (Ribera et al., 2009). Stigma has predominantly been explored in relation to leprosy and has been described as a 'social killer', which is often worse than disease itself(Ribera et al., 2009). However, some argue that stigma has been overplayed within the NTD community, often at the expense of other factors that may lead to social isolation(Ribera et al., 2009). Three core types of stigma are described in relation to NTDs that should be considered(Ribera et al., 2009, Scambler, 1998, Van Elteren, 2017, Weiss, 2008). These are: enacted or experienced stigma, which is based on actions of discrimination by individuals or communities; anticipated stigma in which individuals perceived a likelihood of discrimination based on their impairment or condition; and internalised stigma whereby individuals often withdraw because of negative feelings that they have about themselves.

A recent systematic review that focused on stigma in relation to NTDs, highlighted that all types of stigma were prominent in relation to Leprosy, Lymphatic Filariasis, Podoconiosis, Buruli ulcer, Onchocerciasis and Leishmaniasis. They also found evidence of all types stigma related to Chagas disease, Schistosomiasis, Trachoma and STH, although fewer studies had focused on stigmas associated with these diseases. Explorations of stigma associated with NTDs that cause less visible affects, such as Schistosomiasis, are often less prioritised. This is problematic, particularly

when considering internalised stigmas, and therefore presents a need for greater research into illness experience associated with NTDs that may produce less visible impairment. This is also important when considering long term implications of stigma in association with NTDs, as even when physical impairment may be reversed or minimised, social stigma, particularly that which has caused poor mental health outcomes can last a lifetime(Barrett, 2005). Brieger et al. (1997) found that treatment with Ivermectin alone had no impact on the stigma associated with Oncheral skin disease. This further emphasises the need for more holistic interactional approaches to DMDI in relation to NTDs.

Issues influencing variations in types of stigma experienced have been more widely considered than in relation to gender. In relation to disease stage, Lu et al. (1988) found within India, that enacted stigma experienced increased with disease progression of Lymphatic Filariasis and resultant Lymphoedema or Hydrocele. In addition, the location of hydrocele in relation to LF also caused increased stigma, which was greater when it was in the genitals as opposed to the leg(Lu et al., 1988). Aetiology of disease, as perceived by the communities was also seen to have a bearing on enacted and internalised stigma, although this wasn't the case for all diseases. Schistosomiasis is often perceived to be associated with promiscuity based on signs and symptoms in the urinary tract; however, this was not the case for diseases such as LF and Leprosy. Rather, more physically visible diseases were perceived to be hereditary and therefore stigmatisation tended to be linked to moral constructions of disability that suggest impairment is the result of wrong doing in a previous life.

Disembodiment[8] was also often associated with internalised and anticipated stigmatisation, this was evidenced by observed covering of limbs or lack of their use. Disembodiment has been identified as particularly evident when disease or impairment was acquired in adulthood based on the fact that prototypes of health and normalisation were often learned from a young age(Barrett, 2005). One study noted that when individuals had low incomes, were young and female, they were

[8] Dissociation of physical impairment from consciousness or identity.

likely to experience increased levels of enacted stigma(Hofstraat and van Brakel, 2016). Studies focused on different manifestations of stigma often describe inequities in an additive way or focus on a specific axis of inequity. For example, Van Elteren (2017), suggest that female leprosy patients are more severely affected by leprosy-related stigma than men. Few studies have taken a holistic intersectional approach to inequities and explored their relationship to differing stigmas. This is particularly important when thinking about the design of holistic interventions that are responsive to the needs of all.

Similarities between experience in enacted, anticipated and internalised stigma across a range of NTDs suggests there is scope for more joined-up thinking in relation to stigma management as a component of DMDI. This has been evidenced in the implementation of joint support groups for LF and Leprosy, which have been shown to be a key component of rehabilitation and support to individuals living with these NTDs. The use of support groups has also been effective for individuals living with Podoconoisis and Buruli Ulcer(Agbo et al., 2019, Tsegay et al., 2018); however these groups have been less integrated with other NTD support groups. The similarities in stigma experience between individuals living with NTDs as well as those living with other chronic disabling or stigmatised conditions such as HIV/AIDS also presents a key opportunity for lesson learning regarding stigma management from other non-NTD specific interventions. Such cross programmatic lesson learning is likely to improve understandings of how programmes can be co-implemented and integrated within the broader health system(Hofstraat and van Brakel, 2016).

3.6.4 Conflict, Fragility, NTDs and Disability

During periods of conflict and fragility, including episodes of disease outbreak (e.g. Ebola) or natural disaster (e.g. earthquake), breakdowns in health services or ongoing systems weaknesses, coupled with mass migration, can have negative impact on control of NTDs (Manderson et al., 2009). Additionally, conflict and fragility can exacerbate vulnerabilities for people with disability. During these periods, social support services including those related to health, education or income may be unavailable or inaccessible. For example, during the recent Ebola outbreak in West Africa, many people with disabilities were unable to understand or engage with

health communication messaging as it was ill adapted for their needs, and as a result they were further marginalised and placed at increased risk of infection and associated psychological trauma. In times of war, this can also be the case, particularly for people with sensory impairment, who may find it difficult to interpret what's going on, as well as when and where to flee from danger.

In humanitarian settings, caregivers of persons with disability, particularly parents of children with disability, can face a magnification of vulnerabilities due to challenging environmental, social and cultural factors that result in their exclusion and limited access to services, which is heightened during periods of service scarcity(Zuurmond et al., 2016). For example, children with disability may be more likely to be malnourished in conflict settings but have worse access to feeding programmes(Zuurmond et al., 2016). Having said this, humanitarian assistance in some conflict affected or fragile settings can increase access to services and resources which can be of benefit to people with disabilities – for example, provision of water and sanitation services. Accompanying education programmes can also frequently support in transforming community opinions and perceptions surrounding disability. Conflict and fragility can also cause significant demographic shifts and lead to increases in prevalence of disability due to disease, gender-based violence, injury and greater psychosocial support needs.

3.6.5 NTDs and Mental Health

A review by Litt et al. (2012) suggest that factors associated with NTDs predispose individuals to poor mental health. These include stigma and discrimination, exclusion from participating fully in society, reduced access to health and social services, lack of educational opportunities, exclusion from income-generation and employment opportunities, and restrictions in exercising civil and political rights – especially for those with physical disability and permanent disfigurement(Litt et al., 2012). For example, lower quality of life scores were associated with mental illness in patients with podoconiosis in northern Ethiopia(Mousley et al., 2014). Effects of chronic ill-health and disease are frequently not limited to the affected individual and this is particularly the case for NTDs. However, research is lacking on the impact of NTDs on the mental health of caregivers(Litt et al., 2012). The complex relationship between

NTDs and mental health and the current evidence base is further discussed in Chapter 6 (6.5.1).

3.6.6 NTDs and the Household

Due to the longer-term investment in research into illness experience associated with Leprosy that has focused on social consequence of disease, there is information to suggest that stigma associated with the disease is often inheritable(Barrett, 2005). Goffman (1968) refers to this as a curtesy stigma, whereby individuals within the household suffer social and economic losses due to their affiliation with Leprosy(Barrett, 2005). In relation to Leprosy and economic loss, compounded poverty as a result of Leprosy is often transferred to children. Furthermore in such circumstances the 'begging potential' of children irrespective of their own leprosy status often results in parents being dissuaded from sending children to school(Barrett, 2005). There is some evidence to suggest economic losses of the household as a result of other NTDs, due to family members having to fulfil roles as caregivers and hence presenting a loss of economic productivity within the household. However, little information exists about the subjective associated illness experience of other household members. Disruption to the household as a result of NTDs is a reason for delay in accessing treatment for NTDs particularly by women, as they do not want to disrupt normal routines(Agbo et al., 2019). Understanding how illness affects broader household structures and how this varies by context, household position and axis of inequity is critical when thinking about holistic approaches to the management of NTDs. Not only is curtesy stigma and economic loss thought to affect key individuals within the household, it is also hypothesised that social isolation and abandonment can cause chronic mental health problems within the household. The extent of such factors and how they differ between household members needs to be understood to ensure all individuals can access necessary DMDI services(Mieras et al., 2016, Ribera et al., 2009). Furthermore, as political, economic and social change occurs within many of the contexts in which NTDs are most prevalent, for example as a result of conflict and disease outbreak, it is important to understand how changing household dynamics may influence the

implementation of different NTD interventions(Dean et al., 2019b, United Nations Development Programme, 2019).

3.7 Concluding Thoughts

Chapter one and three have argued that, to date, there has been a dominance of biomedical approaches to health in relation to NTDs. Despite a collective grouping of NTDs, approaches to their management and control have been fragmented and heterogeneous, with minimal co-implementation between NTD programmes and other vertical disease programmes. In addition, NTD interventions have lacked integration within the wider health system, thus contesting their long-term implementation and sustainability. Despite evidence of the mutually reinforcing social and economic implications of NTDs and associated disability, little focus has been given to such issues within NTD control programmes. The multiple and intersecting inequities that shape disease risk and outcome are also seldom explored in tandem and there is a lack of data that fully elucidates the illness experience of NTDs from the perspective of the individual and the household. There is a paradigm shift within the NTD community that suggests the need for increased co-implementation, better integration with the wider health system and more holistic approaches to the management of NTDs including DMDI. Without better understanding of the illness experience associated with NTDs, how this varies by axis of inequality, and between different NTDs, achieving such a paradigm shift is unlikely.

Chapter 4: Methods

4.1 Chapter Overview

A consolidated version of methods that are relevant to each individual results paper are provided within chapters five to seven. This chapter presents the methodological and epistemological foundations for this research study in more detail. Initially, I provide reflections on the origin of this thesis and how it links to the COUNTDOWN consortium. I then provide consideration of the methodological foundations of the study, including documentation of my positionality in relation to intersectional approaches to narrative analysis. Detail on the methods selected, study sites, participant recruitment and analysis are then presented against each study objective. Within the latter sections of the chapter I consider the ethical considerations of my approach, methodological challenges and limitations, and steps taken to improve trustworthiness of the study. Throughout the chapter, I also provide reflections on my positionality and how this may shape narrative interpretations, and conclude with a specific section on reflexivity.

4.1.1 Links to the COUNTDOWN consortium: learning curves and thesis origins

The COUNTDOWN consortium is a multi-country implementation research programme funded through the UK department for international development (DFID), with the overall goal of reducing mortality, morbidity and poverty associated with NTDs. The primary focus of the consortium is on the scale-up of access to MDA for the preventive chemotherapy NTDs[9]. COUNTDOWN has a highly diverse multidisciplinary research team, the majority of whom have worked on NTDs for many decades, predominantly with a parasitological or clinical mandate, focused on a specific disease. In 2015, I began working as a research assistant within the COUNTDOWN consortium, with the initial task of supporting the operationalisation of the 'social science/health systems' theme of work. Over the first few months in my new post, as I began to navigate the complex and inherently political world of NTDs, I had many interesting and informative conversations with my colleagues

[9] Lymphatic filariasis; onchocerciasis; soil transmitted helminths; schistosomiasis; trachoma

about the biological, parasitological, and environmental facets of these diseases all of which were critical in the development of my knowledge base. However, the more time I spent reading, in meetings, and in the presence of 'NTD specialists' I became increasingly aware of the somewhat neo-colonial approach, not only to the value placed on scientific 'truth' or 'method', but also in emphasising a significant gap in the value and visibility of voices or experiences of people, populations and health systems in countries affected by these diseases (see section 2.4 and 3.2.2). This is not to say the people affected by NTDs are not the central focus of many of the people that I have interacted with, particularly given the strong ethos within NTD programming of community centred approaches, however, over time my reflections and observations have left me wondering the extent to which this value remains at the fore for some individuals. At its most extreme the NTD community really could learn from Bowleg (2012) statement that '*fashioning public health messaging from the perspective of white middle class populations does not always equal good public health practice'*(Bowleg, 2012p.e3).

As I began to visit COUNTDOWN research and NTD programme partners in Nigeria, Liberia and Cameroon, I became increasingly bothered by the emphasis that was being placed (normally by MoH donors and NGDO implementing partners) on the apparent 'magic bullet' intervention that MDA presented for the control, management and elimination of many NTDs. I also began to reflect on the under-prioritisation of the care and treatment of people permanently affected by communicable disease in the design and delivery of vertical mass treatment campaigns (such as those for Polio, onchocerciasis, and lymphatic filariasis), designed to eliminate their target disease as a public health problem. Consequently, whilst realising that mass drug administration campaigns for many diseases were necessary, I began to find myself asking again and again; 'what about the people who are already affected by the lifelong morbidity and disability that some of these NTDs present?' I was becoming increasingly interested in understanding how vertical disease programmes that take a very biomedical approach to prevention and treatment of disease could adapt or better integrate with the broader health and social support

systems to understand how the needs of people permanently impacted by disease and disability could be realised.

In early 2016, on a COUNTDOWN visit to Liberia, I was fortunate enough to engage in discussions with the NTD programme manager, Mr Karsor Kollie, who shared with me detail about Liberia's recently developed integrated case management plan. He described to me that the evolution of this plan was to allow for resource maximisation as well as to support the programme to think about how people living with the clinical manifestations of NTDs could be better supported. The purpose he felt, was around 'integration' not only of different NTDs (primarily leprosy, Buruli Ulcer, Yaws, lymphoedema and hydrocele), but also with the broader health system, particularly at the primary healthcare level. I read through the plan, however, I was again left wondering how the priorities of people affected by these different NTDs had fed into the plan's development and how their participation in the plan's adaptation could be facilitated. My discussions with Karsor challenged my assumptions that these populations had been intentionally excluded from participation in the design of programmes that they would hopefully benefit from, or that they were not the central focus of those delivering the programme; rather I realised, that in an overstretched and under-resourced and donor reliant health system, developing person-centred health interventions often requires a multi-step approach. Karsor described the integrated case management plan as the first step on a journey toward developing integrated and holistic care for people affected by NTDs and one that could contribute to supporting to rebuild and strengthen Liberia's health system weakened by war and Ebola. Despite his decades of expertise in this area, he still asked me how to do things better or differently, referring to me as a key 'technical assistant' to him. I was suddenly very aware of my 'whiteness' that a) placed me in an assumed position of power and knowledge amongst my NTD programme colleagues (based on very limited experience within NTDs and within Liberia), based on, what I can only assume is the organisation that I was representing and my geographic origin and b) that my assumptions and 'best intentions' were immediately challenged(Goudge, 2003).

On returning to Liverpool and after much discussion and deliberation with Karsor, and my PhD supervisors, the idea for this study developed. Recognising that I was very much an 'outsider' in a Liberian context and far removed from the realities of individuals affected by NTDs, I began to think critically about the need to develop a set of methods that would create space for people or study participants to guide the content and bring the knowledge and experiences of people affected and Liberian health systems actors to the fore. I realised I had a lot to learn (and still do) about the realities of conducting research in a post-conflict, post-Ebola Liberia. The time I have spent in Liberia, working, and having informal conversations with the NTD programme team, has helped my understandings and will forever change my outlook on conducting research in these settings. However, despite trying as much as possible to embed myself within the Liberian context as well as reading countless books about people's lives and watching many documentaries, I am still very aware that the complexities of life in Liberia is something that I appreciate I will never fully understand. I hope that through ongoing reflexivity throughout the course of my PhD, coupled with the sometimes-relentless questioning of many of my Liberian colleagues and friends, that the analysis of stories presented within this thesis will be as grounded in a Liberian context as possible. Throughout this chapter, I have tried to represent my reflections and positionality in relation to different components of the study as well as trying to think critically about how the deeply complex social and political context of Liberia has shaped findings.

4.2 Methodological Foundations

4.2.1 Narrative Enquiry

Multiple forms of narrative research exist that draw on a broad range of epistemological, ideological and ontological phenomena. Narrative enquiry is the study of the development of social phenomena and points of transition in people's lives and has gained traction within the social sciences based on two parallel processes: 1) the rise of humanist approaches within sociology and psychology that prioritise person-centred approaches and resist positivist empiricism; and 2) a focus on post-structuralist approaches, most interested with story structure and content,

particularly narrative fluidity and the power relations that enable narrative to become possible(Andrews et al., 2013, Parker, 2003). Humanist and post-structuralist approaches to narrative analysis are often brought together and unified by the fact that they treat narratives as modes of resistance to existing power structures. For example, some may investigate biographical expressions of womanhood (Tamboukou, 2010), whereas others may use narratives as forms of therapy to try to change individuals' relationships to their social circumstance(Andrews et al., 2013, Sliep et al., 2004). However, it is the range of philosophical viewpoints underlying these approaches to narrative analysis that lead to ongoing divergence in the conceptualisation of 'what is narrative'? and in the further development of narrative research. Humanist approaches rely on the concept of a singular unified subject, whereas post-structuralist approaches rely on narratives as multiple, continuously constructing based on social processes, and thus are consequently reinterpretable(Andrews et al., 2013, Squire, 2005). Despite these theoretical and conceptual differences many researchers conduct narrative research that spans disciplinary divides to promote innovation and pragmatism.

Within this thesis, I draw on post-structuralist understandings and approaches to narrative enquiry. This is because I believe that narrative enquiry frequently involves a process of co-creation between the researcher and the researched which is inherently social and influenced by relative positions of power within the narrative interaction. Individual realities and understandings are changeable and re-interpretable depending on broader social and structural processes. The narratives shared and analysed within this thesis represent the experience of individuals within a specific time and relationship and their interpretation and re-interpretation becomes dependent on a process of continued reflexivity. Having said this, I do believe that narrative can be drawn upon as a therapeutic resource, particularly in the exploration of chronic illness, disease and disability, which aligns more to humanist approaches within narrative theory. The approach to narrative enquiry taken within this thesis is further described in specific relation to illness narratives within section 4.2.4.

4.2.2 Narrative approaches to 'ill' health

> *'the actions of those hearing a narrative are as central to it as the teller themselves'(Riessman, 1993p86)*

4.2.2.1 What is an illness narrative?

Illness narratives fall within the constructivist paradigm of qualitative research enquiry as they are focused on individual expression of illness as shaped through the lived experience of individuals (Baum, 1995, Pluta et al., 2015). Specifically, they are designed to allow individuals to shape the way in which they talk about their illness in an unstructured manner that other methods situated within this paradigm, such as semi-structured or in-depth interview may not allow (Pluta et al., 2015). Illness narrative re-situates the human as a storyteller, best placed to re-count their own reality, understand events, and reflect on experience based on what is important to them(Hurwitz, 2000, Pluta et al., 2015). A highly narrative approach also aims to redress an imbalance within medical culture, moving away from biomedical standpoint that see disease as problems that need fixing to one that allows deeper appreciation of patients as people. In essence, narratives can span both the medical and the social and thus re-situate medicine between the humanities and the sciences and ultimately allow for more holistic interpretations of health and illness(Hurwitz, 2000).

4.2.2.2 Why Illness Narratives?

Given the historical dominance of biomedical approaches to disease management, disability and inclusion (DMDI) associated with NTDs, and lack of inclusion of people affected by NTDs in policy design and implementation, illness narratives present a useful approach to re-frame such thinking and establish an understanding of living with NTDs from the perspective of affected individuals. In addition, due to a scarcity of information in this area, generation of more structured interviewing techniques would likely shape the way an individual describes their experience based on the investigators' pre-conceptions as opposed to in their own words. This further favours the use of less structured techniques. Illness narratives can take many different structures dependent on subjective experience. Combined analysis across illness

narratives from different individuals living with the same disease has however proven useful in designing rehabilitation programmes and exploring coping mechanisms as common frameworks for understanding the subjective experience. This has been particularly true in the exploration of other chronic disabling conditions, such as stroke(Pluta et al., 2015). Thus, a comparison of illness experience between people living with the same or different NTD(s) may enable the development of similar frameworks for understanding the subjective, which have the potential to contribute to improved understanding of how DMDI strategies could be integrated between NTD programmes or with the wider health system.

4.2.2.3 The narrative debate

Narratives and specifically illness narratives have their routes within sociology and anthropology, both of which can be considered as a value science as they are shaped by the values and belief systems of the researcher(Frank, 2010). Thus, interweaving of discussions of my own positionality throughout this chapter was essential. The narrative debate between *story tellers* vs *story analysts* centres around the extent to which one's own values and principles influence the construction, analysis and interpretation of narrative and to what degree key methodological rules or steps should be taken to manage the influence of researcher position within narrative analysis(Thomas, 2010). The narrative debate is not a debate about establishing a correct or incorrect approach, but one that requires reflection and consideration of the different epistemological standpoints within it to be able to establish an appropriate individual standpoint or approach within this work (Thomas, 2010).

Story Analysts

On one side of the debate, Atkinson (1997) describes the role of the researcher as the *story analyst(Atkinson, 1997)*. They suggest that whilst one cannot ignore the social development of narrative; their construction and analysis should be grounded within and draw upon formal methods used within the social sciences. Specifically, data should be collected and analysed in a methodical way, with findings valued in the same way as those arising from any other form of social action(Atkinson, 2010). Such approaches resist the idea of narrative exceptionalism and would not view

narratives as 'hyperauthentic' forms of knowledge production i.e. one form of knowing and experience should not be prioritised over others(Atkinson, 1997, Atkinson, 2010). Finally, Atkinson would challenge the claim that narrative can be used as a therapeutic resource, and the need for everyone to share their story(Atkinson, 1997, Thomas, 2010).

Story Tellers

On the other side of the debate, sit scholars such as Frank (1995), Kleinman (1980) and Bochner (2001), who see the role of the researcher as the storyteller(Bochner, 2001, Frank, 1995, Kleinman, 1980). Bochner (2010) argues that story analysts want to apply '*methodological sovereignty to the discipline and regulate qualitative inquiry'(Bochner, 2010p 663)*. They suggest that the approach of the story analyst neglects to acknowledge the role of the analyst(s) as part of the story, suggesting that as the storyteller a critical component of narrative analysis is to recognise yourself through a constant process of reflexivity. Thomas (2010) describes this as follows:

> *To witness, to play a part in, and to analyse the project of self-understanding is what makes narrative research both qualitatively distinct and demanding of researcher empathy' (Thomas, 2010p651)*

This links to Kleinman's ideas of empathetic witnessing, through which storytelling is a means of being with others and opening to the unheard. Such approaches require deep and ongoing reflexivity to think about how narrative is shaped and mediated by social and cultural context to allow for the development of personal meanings of suffering and healing (Kleinman, 1980). The importance of critical reflection is not meant to establish narrative as a 'hyperauthentic' but allow the storyteller more freedom to shape the method based on what is being explored (Bochner, 2010). Through this process, storytellers resist a reductionist approach to narrative analysis, in which the dominant voice of medicine normally comes to the fore (Mishler, 2005), by refusing to break narrative down to overarching concepts or debates. Such resistance to methodological rules can be a dangerous concept to academic traditionalists (Thomas, 2010). However, holistic consideration of narrative allows for

the exploration of narratives of resistance that reflect on both narrative content and formation (Mishler, 2005). Frank, as a survivor of cancer, conceptualises the need to consider the position of the storyteller within narrative analysis as 'standpoint theory', arguing that whether or how stories are understood is as much linked to experience of the researcher and the subject as it is to the narrative itself. Frank argues that central to any narrative encounter is ethical interaction, specifically respectful and empathetic interaction, and that this should be prioritised above method, particularly in considering narrative as a therapeutic resource(Frank, 1995). My approach to narrative analysis, positioning and alignment within the narrative debate is further justified in section 4.2.3. Prior to describing my particular standpoint, it is first critical to explore approaches to the application of intersectional analysis.

4.2.3 Applying Intersectionality

Intersectionality becomes essential in health research to ensure that we don't strip away the complexity of people's lives in seeking to understand relationships and responses to health and illness(Bauer, 2014). Intersectional analysis requires consideration of the critical differences between social identity and social position. Identity formation should be considered as a developmental process that is relational based on affiliation or interaction with broader social groupings and is informed by multi-level power relations (Bauer, 2014, Caiola et al., 2014). Processes of identity formation are fluid and can shift through space and time; they are frequently influenced by social position or can result in specific social positions depending on broader contextual factors and thus both identity formation and social position can inform specific health outcomes (Bauer, 2014). By resisting universalism, intersectionality provides a platform for consideration of how processes of identity formation and social position shape broader social constructs such as 'manhood', 'womanhood', 'motherhood', or 'patienthood' and allows critical reflection on the broader social and historical context that informs their constitution(Caiola et al., 2014).

Application of intersectional theory is however methodologically challenging(Bauer, 2014, Hankivsky et al., 2009, Larson et al., 2016, McCall, 2005). A lack of definitive

methods for the exploration of intersectionality has often been the main critique of the theoretical orientation; however, over the last decade best practices and guidance for its application in qualitative and quantitative research have been emerging(Hankivsky, 2012, McCall, 2005, Sen et al., 2009, Sen and Iyer, 2012). Christensen and Jensen (2012), present clearly a series of key issues to guide the application of intersectional analysis suggesting that methodological complexities associated with intersectionality are not weaknesses but new ways of knowing. Primarily, they emphasise the difficultly in considering multi-constitutive processes through the exploration of specific social categories. McCall (2005) links the varying approaches to categorical analysis within intersectional theory to different types of knowledge formation and or approaches within feminist theory. McCall (2005) describes, anti-categorical analysis as resisting the use of social categories completely and aligning with post-structuralist thought; intra-categorical analysis as exploring the experiences of specific sub-groups within larger social categories, for example, Crenshaw's analysis of black women's experience within a white feminist discourse; and their own preference for inter-categorical approaches which seek to explore the complexity and relations between multiple categories of inequality(Christensen and Jensen, 2012, McCall, 2005).

Categorical analysis approaches all have in common that they are 'non-additive' and concerned with how experiences of social difference influence inequities in outcome. Christensen and Jensen (2012), argue that the divergence in ontology of varying forms of social difference, all of which manifest within structural and identity-based inequalities presents another key challenge in applying intersectional analysis. In simple terms, they emphasise that all forms of social difference e.g. gender, class, and race, function differently and so their consideration as 'different types of social category' can become problematic when considering how they converge to shape individual reality. However, in practical terms, it is frequently not possible to explore all axes of power within one empirical study, and therefore at some point a decision must be made as to the most important social stratifications or categories to be explored that can serve as 'anchor points' for deeper analysis (Bowleg, 2012, Christensen and Jensen, 2012). This decision should have a strong rationale and be

based on evidence as well as highlighting what will be missing in the analysis process because of such decision making (Hankivsky, 2012). Casting aside pre-conceptions of which dimensions of oppression may be most dominant, consideration of the power and privilege of majority groups and inclusion of a range of categories e.g. patient, masculinity etc. can be challenging for research teams and requires a great deal of personal reflexivity and ongoing dialogue between research team members (Bowleg, 2012, Christensen and Jensen, 2012, Hankivsky, 2012). Consideration of the possibility of multiple and intersecting axes of oppression and dominance is as critical within sampling as it is within analysis processes (Bowleg, 2012).

Christensen and Jensen (2012 p112) suggest that the *'greatest strength of qualitative intersectional analysis lies in its openness towards the unpredicted and its ability to understand the specific and the local'*. Consequently, they emphasise that although not new in research underpinned by feminist ideals, narrative can be an important tool in intersectional research (Christensen and Jensen, 2012). Narrative in its simplest form can support the process of identity formation in relation to social structures, as the meaning and relations of personal experience are explored and linked to varying social categories (Prins, 2006). Narratives can provide a space to explore and analyse the multiple historical oppressions of the most marginalised from their own vantage point as opposed to as a deviation from 'white, middle class norms' (Bowleg, 2012p e2) and can allow the construction of knowledge and social reality to be guided by participants themselves (Caiola et al., 2014). It can support researchers to experience forced reflexivity around their 'preferred' axis of dominance and oppression by supporting to 'contour the privilege of other voices' that should shape the development of more person-centred health systems (Bowleg, 2012). This is not to argue that narrative and it's use within this thesis offers some form of 'hyperauthentic' truth; rather it provides an opportunity to consider fact within the narrative as well as how diverse social categories interact to give narrative meaning (Christensen and Jensen, 2012). By using everyday life as an entry point, narrative approaches can provide a space to ask about the influence of social categories on experience without having to be too prescriptive. Narratives resist additive approaches as individual stories become a 'melting pot' that allows for in-

depth consideration of a convergence of factors in an intersectional exploration (Christensen and Jensen, 2012).

4.2.4 Intersectional Approaches to Narrative Analysis: What's my position?

> *'As a storyteller (who has occasionally analysed stories too), I am one of those people who think it is important to bear witness to the suffering of sick people. I want to understand what it means to be ill, to provide comfort, to acknowledge suffering, and to pay attention to the tales of wounded storytellers, to take in and resonate with their stories and to better understand what prevents medical practitioners from hearing what their patients tell them and patients from disclosing what they really would like their doctors to know (Bochner, 2010p664).'*

Thomas (2010) describes that in undertaking any form of narrative analysis it is critical to be clear of your own standpoint. They suggest that critical reflection on standpoint can be encouraged by answering four key questions: 1) What type, or types of sociology do I draw upon in the analysis of these illness narratives?; 2) What epistemological status should be attributed to respondent's narratives?; 3) What is my ethical stance?; 4) Does anything go methodologically?(Thomas, 2010)

Intersectional approaches also require a great deal of reflexivity on the part of the research team to assess how the questions they ask are based on their own positionality of power and privilege. My position as an 'outsider' within the Liberian context makes reflexivity in relation to both narrative and intersectional analysis even more important, specifically consideration of how my 'whiteness' may have shaped narrative construction. I have therefore used the questions presented by Thomas (2010) to shape my own reflection and standpoint in the use of intersectional narrative analysis in this thesis.

4.2.4.1 What type, or types of sociology do I draw upon in the analysis of these illness narratives?

Based on my academic training and intellectual development in human and social geographies which are specifically concerned with the spatial relationships and construction of social phenomenon and experience, I subscribe to and draw upon the epistemology of social constructivism within this thesis(Kukla, 2013). Increasing exposure and training in feminist sociologies and intersectional thought have encouraged ongoing and critical reflections regarding how individuals' construction of reality is frequently temporal and mediated by unique and varying positions of power and privilege, underpinned by broader structural and social forces (Collins, 2002). My personal and professional experiences have also led to multiple first-hand interactions with people living with chronic illness and disability that have had life altering consequences, predominantly in a UK context, but also when living and working in other low- and middle-income country contexts. These interactions shape my understanding and response (both professionally and emotionally) toward the stories and narratives collected within this PhD thesis.

Consequently, I find myself in alignment with Bochner, Frank and Kleinman, as a 'story teller' (see section 4.2.2.3) in that I cannot extract my role in the construction and interpretation of these narratives, but that the analytical process demands ongoing and thorough reflexivity in inferring the personal meaning of suffering expressed by individuals within case studies collected. This aligns to post-structuralist approaches to narrative analysis. A critical reflection at this point, is in my position as an 'outsider', despite deep immersion over several years in the Liberian context, my interpretation and analysis of narrative in this thesis draws predominantly on my ethnographic experience. Ultimately, I believe that the stories shared with me in the process of data collection are socially constructed and centred around what being affected by NTDs means to an individual, i.e. they represent a sharing of individual realities within a particular relationship at a particular time. As Thomas (2010) argues, from a standpoint such as this, to suggest that objective interpretation of narrative from a position of neutrality is possible would be false and thus continued

reflection on one's own position is critical and embedded throughout this methods chapter and thesis.

This thesis was particularly concerned with narrative threads including: narrated illness experiences and how these are mediated by broader structural and social context, how this varies through place and time, and the links between disease and disability. Ultimately, this expands Mishler's ideas that social and economic inequality should be considered in narrative analysis to suggest a need for a merging of concepts to include consideration of intersectionality; this allows for analytical thought to be given as to how structural and social condition shapes the construction of social identity, emotional, and physical response during a period of significant change (Christensen and Jensen, 2012). As I am not trained in the provision of psycho-therapy, my skillset does not allow for critical appraisal of narrative construction as a 'therapeutic resource' (Kleinman, 1980, Bochner, 2001), rather I sought to empathise with study participants and to consider the health system responses to experiences shared and, based on my position of relative power, use such narrative as a tool to recommend action and support for the people concerned.

4.2.4.2 What epistemological status should be attributed to respondent's narratives?

The stories told by people affected by NTDs and members of their household within this thesis are socially constructed accounts. The very process of narrative construction will have contributed to the ways in which individuals interpret the meanings of things they have experienced and how they choose to articulate them. The narrative interaction was designed to encourage participant and researcher engagement; participants were not considered as subjects within a research process, rather through the sharing of stories it was anticipated that a mutual process of 'conscientisation' may occur (Caiola et al., 2014, Freire, 1996). These narratives are not 'hyperauthentic', nor do they present greater validity than other types of qualitative data, rather they are one subjection of reality that adds value in that the socially constructed knowledge from affected individuals differs from the knowledge held by clinicians and public health practitioners. The social foundations of these

types of knowledge are different; in my experience many of those who design and deliver the response to these diseases prioritise clinical or scientific knowledge as 'truth' as opposed to a knowledge that is shaped by individual experience. How this knowledge is presented, used and acted upon throughout the development of this work has been a key ethical dilemma and one that I may still not have got right.

4.2.4.3 What is my ethical stance?

There are multiple power imbalances within global or international health and within health service delivery in Liberia. All these power imbalances shape my interpretations of narrative as well as individual's stories, most specifically at the individual or household level are the power dynamics between a 'patient' and 'healer' (both formal or informal). I am aware of these power imbalances, have witnessed them first hand, and am challenged by them every day through my professional position as a researcher working in the global north reflecting on issues affecting those in Liberia and other contexts in the global south. As such, to approach narrative analysis from neutrality is not possible; I, like Frank and Thomas, approached the process of narrative development with the expectation that I would find many instances of disempowerment that are shaped by broader socio-political structures. Kleinman would describe this as a pre-exposure to 'empathetic witnessing', whilst Atkinson may challenge this approach as 'unscientific' and stress a need for more robust and structured analysis. I think I sit somewhere in the middle. A pre-exposure to 'empathetic witnessing' certainly made parts of the stories heard within this thesis emotionally difficult and evoked responses of frustration and or anger toward unjust or unfair socio-political circumstance. However, this made it more important to me to avoid notions of *sentimentality* or *romanticism* in analysis as Atkinson would suggest such a response may provoke; rather it became critical to develop an approach to analysis that was robust enough to ensure a fair and accurate representation of the realities of persons affected by NTDs. Only when this is achieved did I think it was possible to be able to contribute toward an ethic of humane care within NTD service delivery.

4.2.4.4 Does anything 'go' methodologically?

Whilst my sociological position may align more to those of Frank, Bochner and Mishler, I value the need for an ordered approach to analysis presented by 'story analysts' (see section 4.2.3.1) such as Atkinson and Thomas as an essential strategy in ensuring rigour within the analytical process. Bochner (2010) describes that identifying what counts as rigorous narrative analysis is still an unchartered terrain. They describe narrative analysis as a 'living dialogue' so that the story, the storyteller and the narrative analyst are in mutual appreciation of each other(Bochner, 2010). The balance between these positions was something that I found particularly challenging when developing an approach to analysis that allowed scope for a rigorous systemic approach (as the narrative analyst) as well as flexibility and open-mindedness (as the storyteller) whilst also allowing for the story to be considered holistically. Consequently, I drew on multiple types of thematic qualitative analysis that allowed for systematic consideration of the data but did not chop the data into small unconnected pieces but instead allowed for ongoing critical reflection of the story and my position within the narrative generation (see section 4.7.5). Critical reflection was important to ensure the same emphasis was given to positive elements in narrative accounts as was given to more negative elements, particularly given my pre-disposition toward 'empathetic witnessing'.

From an intersectional perspective, I have taken both an intra- and inter-categorical approach to explore differences between as well as within different social categories. Given the focus of this work is primarily concerned with how disease, gender and age interact to shape illness experience these categories have been chosen as key 'anchor points' in my approach to both sampling and analysis. Other 'social categories' are however still relevant, and the fluidity of the narrative approach allows for the evolution and dominance of new categories to emerge throughout the course of this work. I have aimed to use a combination of narrative analysis that allows for deep exploration of identify formation at the micro level, with intersectional analysis that allows for exploration of how an individuals' unique position is shaped by social and structural processes at the macro level presents a unique opportunity to explore how

the manifestation of power in particular locations and contexts can shape illness experience (Christensen and Jensen, 2012).

4.2.5 Constructing Gender

Gender as a relational power dynamic is described in section 1.2.3. Relational theory (Connell, 2012) that aligns to post-structural thought allows for the consideration of how gender as a multi-dimensional power relationship operates in a complex web of institutions(Connell, 2012). Consequently, relational theory is a useful concept in understanding gendered embodiment and its connection to health issues(Connell, 2012). However, understanding how gender operates across cultural contexts and beyond one's local arena becomes challenging in global health research(Connell, 2012). Gender roles, relations and identities are negotiated and contingent with place; my position as an 'outsider' in Liberia would undoubtably shape the ways in which gender and its impact on health outcomes is described and interpreted(Riley and Dodson, 2016). Power dynamics within research shape the construction of gendered realities (Tolo Østebø, 2015) and acknowledging this is essential to support the development of gendered analysis that is sensitive to context, histories and performance identities so as to be able to advance gender and development theory. Thus, my approach to gender within this study is non-essentialist and relational. In applying a relational approach to gendered analysis, I am particularly mindful of Liberia's unique colonial history and ongoing processes of structural violence as a result of globalisation, aid dependency and chronic fragility that shape ongoing health inequities. However, in line with African feminist approaches, I resist victimisation and acknowledge the role of African women, particularly in Liberia, as agents of social change. This analysis is inherently political and considers the strength of survival of both women and men affected by NTDs in an uncertain context(Cruz, 2015).

Gender is used as an anchor for an in-depth intersectional analysis through its use within sampling and the influence of gender analysis frameworks within analysis processes. There is frequently a gap in gender theory and the conceptualisation of sex and gender in health systems and programming. In my experience, sex and gender are frequently used interchangeably, and gender viewed from a binary

perspective. This has begun to shift in some health fields and programming, for example, the HIV community is progressive in this area, however, within NTDs a predominantly binary approach to gender remains. Furthermore, to my understanding there has been minimal research undertaken in Liberia to explore the construction of gender and how ideas around women's rights and feminist ideas are translated from the level of international discourse to local contexts (Tolo Østebø, 2015). Consequently, in sampling within this study, gender descriptors of men and women are used as this is what is most appropriate within the study setting. The addition of other gendered identities within the sampling frame would have been unsuccessful in supporting participant identification and in developing an approach to sampling that is culturally acceptable. Despite gender categorisation in this way, it is important to recognise that no pre-conceptions of what these gendered identities mean to individuals was made. Understandings of gender were shaped by descriptions within participant narratives and contextual observations, within the limitations of my position as an outsider described above. This is particularly important in the application of feminist theory in an African context; there is much to be learnt about the construction and communication of gender based on observations of collective organisation and interaction as opposed to a sole focus on what is said or heard(Cruz, 2015).

4.2.6 Constructing Disability

Chapter 3 (section 3.4) outlines models of disability. My approach to disability within this study, is routed within a rights-based discourse, and is underpinned by the fundamental belief and value that persons living with disability have equal rights to social and economic participation. Given the focus of this work on understanding the links between chronic disease and disability through the case study of NTDs, I also draw on interactional models (section 3.4) that allow for consideration of how challenges in functioning or capacity can interact within various social structures and environment(s) leading to resultant disability. Drawing most specifically on the capability approach, and through the process of narrative analysis, consideration will be given as to how individuals construct and conceptualise their illness in relation to disability based on individual characteristics, available resources and their

environment and their ability to convert resources into associated capabilities and functioning. In essence, it will allow for an exploration of how changes to the physical self can result in the broader social experience of dis/ability.

4.3 Methods Selected

The following methods and participants were selected to meet each study objective (described in section 1.4) and are discussed in detail in the subsequent sections.

Table 2: Study Objectives, Methods and Participants

Objective	**Method**	**Participants**
1. To understand the Liberian health systems response to chronic disease and disability in specific relationship to onchocerciasis, Buruli ulcer, lymphoedema, hydrocele and leprosy.	Key informant interviews Reflexive diary documenting the delivery of the integrated case management plan.	-National NTD programme implementers -County health staff engaged with the NTD programme -Mental Health service providers at the national and county level -National representatives of disabled persons' organisations
2. To understand individual experience of living with one or more of selected NTDs from the perspective of affected individuals and members of their household with a focus on how this varies by differing axes of inequality such as age, disability and gender.	Illness narratives with people affected by one or more of selected NTDs. In-depth interviews with at least one member of the affected individuals' household. As a set form one 'case study' of illness experience.	-Persons' living with NTDs and affected members of their household
3. To elucidate what medical, social and economic strategies would allow for more equitable and effective support and management for selected NTDs from the perspective of affected individuals, with exploration of how such strategies could be integrated between diseases and within the wider health	Cumulative analysis of previous methods. Dissemination Meetings.	-As above -National and international stakeholders engaged in NTD programme delivery, the provision of mental and social support services for persons affected by

systems response to chronic disease and disability.		chronic disease and disability.

4.3.1 Disease Focus

Liberia's integrated case management plan focuses on; Leprosy, Buruli ulcer, Yaws, and clinical manifestations of LF, including lymphoedema and hydrocele. Leprosy, Buruli ulcer and clinical manifestations of LF are the focus of this study. Yaws has been excluded because: when this study commenced cases of Yaws were not yet identified in Liberia; Yaws manifests predominantly in children who it would have been difficult to engage with using these methods; and there is growing evidence to suggest Yaws should be treated using mass drug administration therapies suggesting alignment to prevention, control and treatment strategies as oppose to those that are focused on long term clinical and social management(Mitjà et al., 2015). Onchocerciasis is currently excluded from the integrated case management plan; however, onchocerciasis is known to have associated severe physical and psychological morbidity. Onchocerciasis is often excluded from such strategies based on rapid reduction in incidence of the disease. However, there are still large numbers of individuals living with lifelong morbidity because of onchocerciasis, particularly in highly endemic countries such as Liberia, who should be considered within health systems responses to chronic disease and disability. Onchocerciasis was therefore also included within this study.

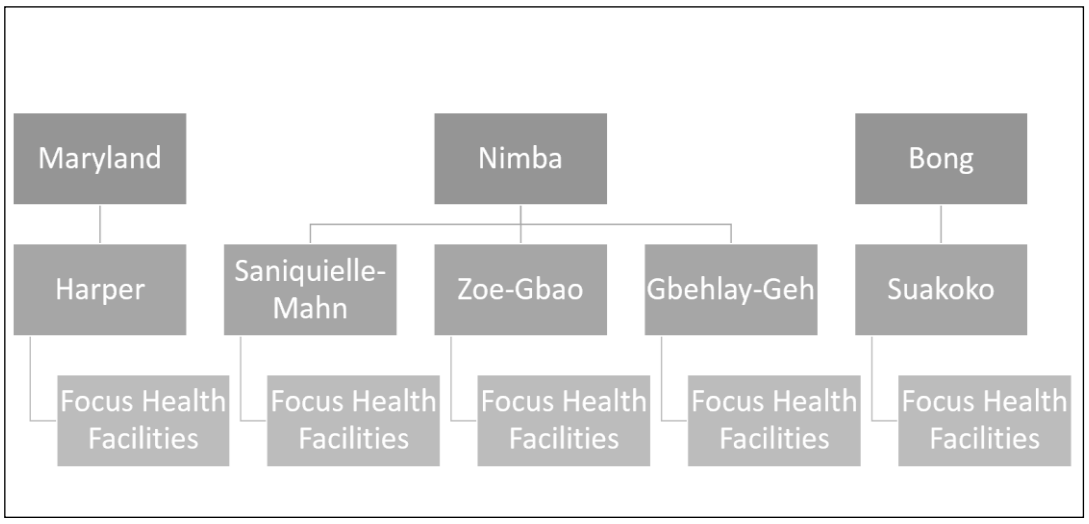
Using disease or clinical manifestations as an entry point to illness narrative case studies aligns to bio-medical approaches to ill-health (see section 3.2). This is contradictory to the ethos and methodological underpinnings of this study, however, within the Liberian health system, chronic illness is currently managed based on perceived causation and bio-medical construction of disease. This is emphasised by the disease specific structure and focus of the integrated case management plan, although the move toward integration of diseases is a key step in a move away from disease specific programming. Conceptualising disease in this way was however necessary to: a) identify potential study participants; b) ensure study findings were as relevant to ongoing programme and policy infrastructure as possible and c)

support the uptake of recommendations for change within existing health systems structures.

4.4 Selection of Study Sites

Data was collected across three study counties, and one district in Bong and Maryland and three districts in Nimba. Within each district focus health facilities were also selected. Study site selection was all purposive and cascaded downward to facility level as shown in Figure 2 and described in the following section. Each study county represented a separate fieldwork visit to Liberia lasting between 4-8 weeks.

Figure 2: Study Site Selection Cascade



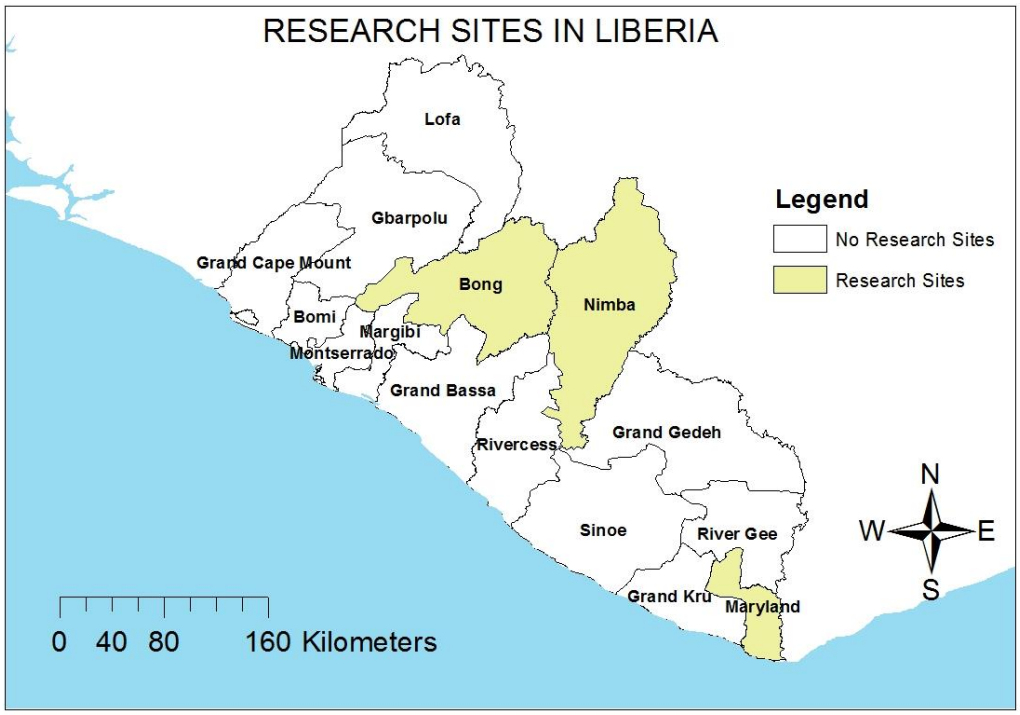
Study counties were purposively selected in collaboration with the Ministry of Health, NTD programme manager, to assist in ensuring relevance of findings to programmatic activities. Three study counties were chosen: Bong, Maryland and Nimba (see Figure 3) based on the following factors:

- Known to have high rates of morbidity associated with one or more of the case management NTDs endemic to Liberia and of focus within this study. This varied between counties. For example, Maryland has high rates of lymphoedema and hydrocele as well as known cases of Buruli Ulcer. Nimba is known to have cases of Buruli Ulcer, Onchocerciasis and active transmission of leprosy, with more than one new case per 10,000 being identified. Bong

county is known to have cases of onchocerciasis and leprosy. Despite variance in known rates of morbidity, all counties are endemic for all diseases.

- The NTD case management plan is currently being implemented with support from AIM International (the key case management implementing partner) in these areas and/or they are of critical programmatic importance, for example, 'Ganta Rehab' is located in Nimba county and is one of the main referral centers for complex NTD cases.
- To ensure variation in geographical location and socio-cultural context (described below).

Figure 3: Research Counties in Liberia



Maryland County has a population of approximately 136,000 which sits roughly in the middle in relation to county population size (Government of the Repulic of Liberia, 2008). Maryland is classified as having a dense population with 100-200 persons per square mile. Located in the South-East, Maryland shares a common border with Ivory Coast and was one of the counties least affected by the Ebola outbreak reporting 34 cases and 28 deaths (figures from early 2015) (Bell et al.,

2017). Forty-seven percent of women are literate compared to 75% of men. The major tribal groupings are Grebo and Kru.

Nimba County has a population of approximately 462,000 and is the second most populous county after Montserrado (Government of the Repulic of Liberia, 2008). Nimba is classified as having a dense population with 100-200 persons per square mile. Located in the North-Central region, Nimba shares a common border with Guinea and Ivory Coast and was significantly affected by the Ebola outbreak reporting 360 cases and 71 deaths (figures from early 2015) (Bell et al., 2017). Forty percent of women are literate compared to 64% of men. The major tribal groupings are Gio and Mano.

Bong County has a population of approximately 330,000 and is the third most populous county in Liberia following Montserrado and Nimba (Government of the Repulic of Liberia, 2008). Bong is classified as having a moderate population density with 50-99 persons per square mile. Located in the North-Central region it shares a common border with Guinea and was one of the counties worst affected by the Ebola outbreak reporting 712 cases and 176 deaths (figures from early 2015) (Bell et al., 2017). Twenty percent of women are literate compared to 53% of men. The major tribal grouping is Kpelleh.

Within each study county, study districts were further purposively selected in collaboration with the NTD focal point within the county health team. To select study districts, data from the most recent round of MDA was utilized to identify areas with a high number of people affected by the NTDs of interest. This was the first MDA that had utilized a case identification method whereby Community Drug Distributors (CDDs) had indicated in community registers where they had identified patients with suspected cases of lymphoedema, hydrocele, Buruli Ulcer or leprosy during routine medicine delivery. Cases identified had not yet been verified but provided an indication of areas that had a high number of people affected by NTDs. In addition to the utilization of data collected during the previous MDA, tacit knowledge of the NTD focal point was used to identify areas where there were known high levels of morbidity linked to the specific NTDs that were of focus in that county. This was particularly the case in identifying cases of onchocerciasis as these are not currently

recorded in routine health systems monitoring activities. As a result, in both Bong and Nimba (known to have a high burden of onchocerciasis), study districts were selected that had known black fly (onchocerciasis vector) breeding sites (fast flowing rivers) within them. Maximum variation across study districts was also aimed for in geography (rural/peri-urban location/border/non-border) and socio-cultural context.

In Nimba, Saniquielle-Mahn, Zoe-Gbao and Gbehlay-Geh districts were selected. Multiple districts were chosen in this county due to the spread of disease cases identified and to explore illness experience within districts that have international borders. Saniquielle-Mahn has a population of 25,000 and is located in northern Nimba bordering Guinea. Gbehlay-Geh is next to Saniquielle-Mahn and has a population of 32,000 bordering Ivory Coast. Zoe-Gbao is in central Nimba and has a population of 29,000. In Nimba county, data was also collected in and around Ganta Rehab facility. Ganta Rehab or 'Liberian Leprosy and Tuberculosis Rehabilitation Center' has been supported since 1974 by the German Leprosy Relief Association-DAHW). Ganta Rehab focuses on active case finding for Leprosy patients (and now other patients living with diseases identified within the integrated case management plan) as well as the provision of medical and social care.

In Maryland, Harper district was chosen. Harper district is in the south of Maryland and has a population of 38,000. In Bong, Suakoko district was selected. Suakoko is in the centre of Bong county and has a population of 30,000.

Harper and Suakoko were also COUNTDOWN study districts. Overlap in site selection allowed me to support ongoing data collection for the COUNTDOWN project as well as longer and repeated field visits to these locations which supported in developing deeper contextual understandings of the areas.

Within each county, records at the main referral facility were also used to identify specific participants or cases where necessary. This worked differently in each study district and is described in more detail in the participant recruitment section linked to the corresponding method in the proceeding sections (see section 4.7.2.1 and 4.7.3.1).

Once study districts had been selected, health facilities were further selected so that participants could be identified from that facilities catchment area based on facility records, specifically CDD registers from the previous MDA cycle. Facility selection was done in collaboration with the county health team NTD focal point and district health officer (where available) based on the same selection criteria as selected study districts. The name of facilities and their associated communities is not detailed to ensure that the identity of participants is protected.

For details of participant recruitment, please see the relevant method in the proceeding sections.

4.5 Selection of a Research Assistant

During my first PhD field visit I decided to recruit a research assistant who would be able to support the data collection process, particularly in navigating 'Liberian English'. After consultation with the NTD programme director, we decided it would be good if this person was medically trained and had experience of working in remote communities so that they could support in disease identification and community entry. The NTD programme director set up a meeting for me with Gartee Nallo. Gartee, a Liberian nursing graduate, in her late 20s, described to me how she had previously worked as nurse in a rural area for the government of Liberia before moving on to work for MSF and other international NGDOs during the Ebola epidemic. Following the Ebola epidemic, Gartee described how she had developed an interest in public health and health systems research and was keen to work with me to build skills in this area. We agreed that Gartee would spend the following week with me and the rest of the COUNTDOWN team where I would train them all in qualitative research methods. I also facilitated one to one training with Gartee on narrative approaches and the specifics of the illness narrative method that we would use in our interviews. Mr Anthony Bettee, staff of the national NTD programme and COUNTDOWN consortium also conducted overview training for Gartee on the identification of the specific NTDs that were relevant to this study. At the end of the training period it was agreed that Gartee would support me throughout the course of my data collection.

Gartee's training as a nurse was particularly helpful in the context, particularly in supporting with patient identification and in understanding bio-medical impacts of the diseases under study. Her experience of working within the health system in Liberia also helped in navigating the health systems infrastructure at county and community level to ensure appropriate permissions were obtained and relevant processes and procedures followed. Gartee, although a Liberian national, as part of a more educated Liberian elite, living and working in Monrovia, was also a relative 'outsider' in many of the study communities. Given historical and political fractions between different sub-populations of Liberian society, particularly between populations living in the counties and an 'elite settler' population living in Monrovia, critical reflection on Gartee's position as an 'outsider' and its impact on the data was particularly important and something which we discussed at great length during debrief sessions. Gartee openly reflected that the interactions with patients and communities throughout the study enabled her to '*learn a lot about her own country'*. Despite the need for these critical reflections, Gartee's deep understanding of the Liberian context, including in many of the study communities based on her professional experience was invaluable in considering the meaning of certain interactions and in clarifying my own understandings. Other members of the wider national NTD programme team were also of critical support in understanding the context of specific interactions and in supporting participant recruitment. When interacting with the NTD programme team, it was however important again for me to consider their relative position as 'outsiders' and their interests and interpretation of specific programme elements. These were important elements for me to consider when seeking their support in understanding the context and meaning of specific interactions with community members. For example, when sharing challenges raised by participants about inability to access necessary medicines, programme staff sometimes became defensive suggesting that this was due to patient error or mis-understanding rather than systems failings.

4.6 Objective One: To understand the Liberian health systems response to chronic disease and disability in specific relationship to onchocerciasis, Buruli ulcer, lymphoedema, hydrocele and leprosy.

4.6.1 Key Informant Interviews

Semi-structured interviews were conducted with key informants at the national and county level to understand the current context of disability in Liberia, with specific focus on the relationship between disability and disease (particularly NTDs), as well as social and health systems responses. Two interview topic guides for key informants were developed (see Appendix 1). One topic guide was used for NTD specific key informants and contained questions linked to key thematic areas including: disability and NTDs in Liberia; generation and content of the integrated case management plan; implementation of integrated disease management; and exploration of key strengths and challenges for disease management. A second topic guide was used with non-NTD specific key informants (e.g. mental health practitioners) to enhance understandings of the context in relation to mental health and disability in Liberia, as well as to support in solution development to key challenges based on the presentation of vignettes to participants that drew on stories told within illness narrative case studies. At the national level, I conducted most of the key informant interviews in English. At the county level, Gartee conducted most of the key informants in Liberian English. I was present for all county level interviews and able to ask follow-up questions and provide clarity to Gartee where necessary. Following each county level interview, Gartee and I would discuss key issues arising based on notes and reflections we had both made during the interview.

Key informants were purposively selected based on their job role and included: representatives from NGOs currently functioning as implementing partners for the NTD programme in Liberia; representatives from the National Ministry of Health linked to the NTD, rehabilitation, or mental health departments; representatives of disabled peoples' organisations, specifically the national union of disabled organisations; and members of the county health team responsible for NTD programme delivery in selected counties. Depending on the role and function of the

key informant, in some instances they were asked to reflect on their own viewpoints and experiences and in others the viewpoint of the programme or their organisation.

4.6.2 Participant Recruitment Process

Participants were contacted by phone and asked to participate in the study. The purpose of the interview was made clear to each participant and a time, date and location for the interview arranged. On meeting, prior to the interview commencing, participant information sheets were shared with participants, they were given the opportunity to answer any questions and informed consent was obtained. Interviews were recorded using a dictaphone once consent for this was provided by participants.

4.6.3 Description of participants

Thirteen individual key informant interviews and one paired key informant interview were conducted. Participants included: 4 national NTD programme staff; 2 international NGDO staff; 2 county level NTD programme staff; 4 national Ministry of Health staff linked to disability and or mental health; and 2 county level staff linked to disability or mental health.

4.6.4 Reflexive Diary

Since 2016 when I first began travelling to Liberia, I have kept a detailed field diary of reflections and observations made. Within my role as a research associate with the COUNTDOWN consortium, other small research grants that I have since been awarded, and during this PhD research, I have been asked to attend a series of Ministry of Health planning meetings that are pertinent to the implementation and development of the integrated case management strategy as well as the broader NTD programme. I have also made several connections and links with a community of researchers, programme implementers, and patient or rights advocates working on issues of mental health and disability. This again led me to be invited to several meetings and workshops focused around these issues in Liberia. Following these meetings and workshops, I reflected on interactions and discussions during the meetings that could inform understandings of the context of NTD policy and programme implementation as well as my interpretation of narrative meaning.

Finally, during my fieldwork visits to counties and communities, I continued to keep a record of my observations within my field diary to encourage continued reflection on context.

4.6.5 Data Analysis

Gartee transcribed all key informant interviews into English or Liberian English depending on the language that the interview was conducted in. Where transcription was completed in Liberian English that was not possible for me to understand, Gartee provided a translation of meaning in brackets at the end of specific sections. These interpretations or translations were anonymised and checked by two other members of the COUNTDOWN Liberia study team. Notes from my reflexive diary were also typed up and if required points of clarity discussed with Gartee and other members of the NTD programme team.

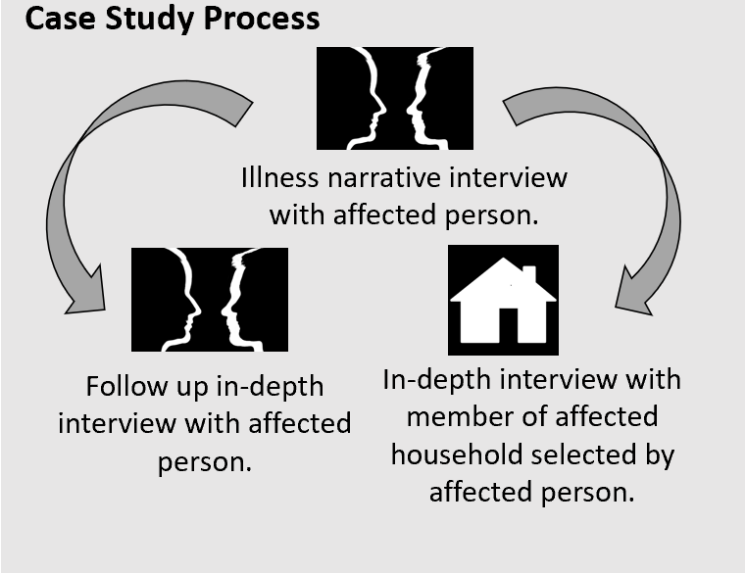
I completed a thematic analysis of all transcripts and notes from my reflexive diary. Thematic analysis involved familiarising myself with the transcripts to develop a coding framework, applying this coding framework to the data (using NVIVO 11 software), and charting the data into broader themes to develop a more explanatory account of the context in relation to disability, chronic disease and NTDs in Liberia (Ritchie et al., 2013). Coding and charting were iterative. Data from key informant accounts and observations from my reflexive diary are drawn upon throughout this thesis to provide a rich and detailed understanding of the context in Liberia in relation to chronic disease, disability and NTDs; to situate study findings within this context; to enhance the trustworthiness of the research process; and to support in the generation of solutions and recommendations that can promote the development and delivery of more person-centred services for people affected by NTDs in Liberia.

4.7 Objective Two: To understand individual experience of living with one or more of selected NTDs from the perspective of infected individuals and affected members of their household with a focus on how this varies by differing axes of inequality such as age and gender.

4.7.1 Understanding disease experience at the individual and household level: A case study approach

A case study approach was used to explore illness experience from the perspective of individuals living with clinical manifestations of one or more of the identified NTDs as well as one member of their household (Figure 4). Illness narratives were developed through at least two interviews with the affected individual. One semi-structured interview was also completed (where possible) with a member of their household or immediate support network. This household member was selected by the individual affected based on their importance in the individuals' story.

Figure 4: Case Study Process

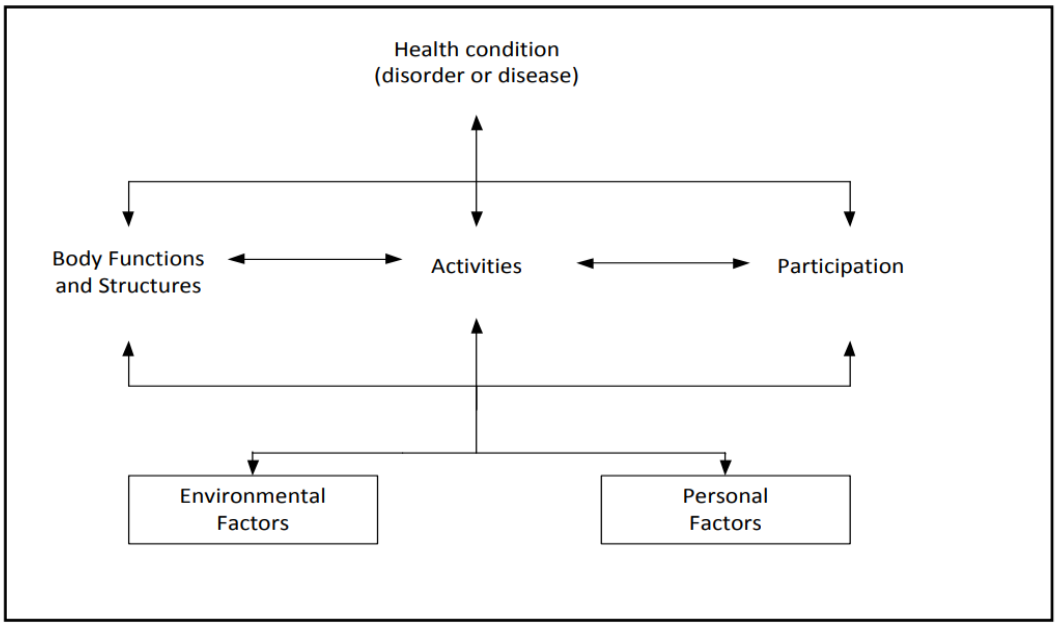


4.7.2 Narratives with individuals living with one or more NTD

Illness narratives often take a highly unstructured approach to allow for a greater detail of subjective reflection and ask an individual very broad-based question, such as; can you tell me about your illness; and how has your life changed because of your illness? (Pluta et al., 2015). During the initial interview with participants, a similar

highly unstructured approach to generating illness narrative was taken within this study, however a few modifications were made to allow for gentle guidance of the research participants toward themes (Thomas et al., 2009). A topic guide was developed, which rather than detailing specific questions, was structured around points or topics that could be addressed using a broad open-ended style of questioning. The guide or framework for the initial interview drew on life history approaches to understand participants' background, before focusing in on the illness experience linked to NTDs. As the study is particularly interested in links between NTDs and disability, focus areas to be included within the topic guides were generated linked to areas of participation as guided by the international classification of functioning (see figure 5). Participation domains included: learning and applying knowledge; general tasks and demand (such as daily routine); communication; mobility; self-care; domestic life; interpersonal interactions and relationships; major life areas (such as education and employment); and community and social life. Although these areas were identified as important if the natural flow of the discussion did not allow for them to be raised, they were explored during the follow up interviews (see Appendix 2).

Figure 5: International Classification of Functioning Framework (World Health Organization, 2001)



Following completion of the first interview, we listened to the audio recording and identified specific areas of the participants' story that we wanted to explore in more detail. We also identified specific themes (from the topic guide) that were unexplored in the initial dialogue. From this a list of key areas or questions to be explored in a follow up interview with participants was identified. During the follow up interview all participants were also asked to reflect on medical or social interventions that they have experienced and link these to living with an NTD, as well as making recommendations for what they perceived to be their key support needs.

4.7.2.1 Participant Selection and Recruitment

At facility level, a sampling frame of all participants living with clinical manifestations of the diseases of interest was developed based on cases recorded within CDD registers. From this, a purposive sample of participants was taken to ensure maximum variation in age, gender and clinical manifestation or disability. Details of the sample are provided in Table 3 below and summaries of diversity in participant characteristic emphasised in Appendix 3. Once identified, the CDD or CHA within the community took us to potential participants in their homes, we were then introduced to participants and given the opportunity to explain the research study. If participants were unable to communicate in Liberian English, CDDs or CHAs were engaged as a translator and used to carry out concurrent translation. We engaged with the same CDD or CHA per-community for all visits. Once the study had been initially explained to the participant, they were given the opportunity to ask questions and left with an information sheet (where literate). If they were willing to participate we arranged a convenient time to return to collect the first narrative interview. On returning to participants, they were again given the opportunity to ask any questions following re-explanation of the study. Informed consent was then taken from participants prior to beginning the narrative interview.

Due to the absence of recording of people living with onchocerciasis within CDD registers, multiple sampling strategies were taken. In Nimba county, we relied on the in-depth knowledge of the NTD focal person to identify persons affected by onchocerciasis. The focal point had been based in the county for his whole professional career and had served as the officer in charge of a health facility in a

highly endemic area for onchocerciasis. Consequently, he was aware of several individuals who were blind because of the disease, these individuals were sampled opportunistically, and invited to take part in the research study as described above. In Bong county, to identify additional persons living with onchocerciasis, with the support of the former national onchocerciasis programme co-ordinator (now serving as the schistosomiasis programme co-ordinator), we reviewed the county referral hospital skin snip register. This allowed us to generate a sample frame of people who had tested positive for onchocerciasis following presentation at this facility or primary health care facilities showing signs of onchocerciasis. From this sample frame, we then took a purposive sample of patients to be recruited to try to ensure maximum variation in the gender and generation of participants. The county health team then supported us to locate potential participants and the same recruitment process was followed as at facility level.

In Nimba county, as well as using CDD registers to identify possible participants, we also utilised Ganta Rehab's clinic records to recruit leprosy and BU patients from the surrounding communities. A sub-sample of in-patients within Ganta Rehab who were currently being treated for Leprosy and BU was also purposively identified from a sample frame of all patients currently receiving treatment at the facility. This allowed for consideration of variation in experience based on treatment type, and duration of disease/illness experience.

Snowball sampling was considered in instances where it was challenging to locate people affected and to try and increase the participation of individuals not already known to the health system. However, this approach was not utilised for three key reasons: 1) due to the remote rural nature of Liberia, even in areas where multiple affected people live, it was infrequent that they knew or interacted with each other; 2) we were cautious to engage with individuals who we already knew were relatively aware of their health condition, and who we could link with subsequent support services. In locating other individuals through snowballing, we were concerned this would involve additional steps of explaining to participants what we perceived to be there health condition which may have brought unnecessary trauma or distress; and 3) due to the highly stigmatising nature of these diseases we wanted to ensure that

participant identity was protected, which we felt a snowballing approach may jeopardise. In instances where people affected identified were not already engaged with the health system, their location was provided to the NTD programme to make any necessary contact. Additionally, through the use of purposive sampling we were able to recruit sufficient numbers of participants to engage within the study and so a snowball approach was not required.

All interviews and follow-up interviews were completed at a location of the participants choice. We tried to limit the number of people present at the interview to myself, Gartee, the participant and where necessary a CDD or CHA acting as a translator. Participants were provided with a bar of soap following completion of both interviews as a token of appreciation. Soap was chosen due to its medicinal benefit for persons living with lymphoedema and was also valued by other participants.

4.7.3 In-depth interview with individual in the household of person living with an NTD

These in-depth interviews used a slightly more 'traditional' approach, which covered core areas of questioning. Participants were asked about: knowledge and perceptions of disease and or disability affecting the household; impact of the disease on relationships within the household; impact of the disease on daily routine and economic situation (income and expenditure) of the household; community reaction to the affected individual and the household; impact of the disease on the affected family member; and possible support interventions that would be of benefit to the affected household member or broader household. Depth of information was encouraged using probes and prompts (see Appendix 2).

4.7.3.1 Participant Selection and Recruitment

Once identified as key individuals within 'patient' narratives, household members were approached to take part in the study. Normally we were introduced to household members by the 'patient' themselves who then assisted in explaining the study purpose. Participants were given the opportunity to ask questions and a suitable time for interviews identified. On return and prior to interview, participants

were asked to provide informed consent. Interview location was decided by the participant and the same persons present as with the patient narrative (excluding the affected person). Participants were provided with a small snack as a token of appreciation for taking part in the research study.

4.7.4 Description of Participants

Overall 27 case studies were completed with participants with clinical manifestations across the four diseases of interest. A summary of case studies is provided in Table 3. Specific participant details are outlined in Table 4.

Table 3: Summary of Case Studies Completed

	Age[10]	Lymphatic Filariasis	Buruli Ulcer	Onchocerciasis	Leprosy	Total	
Men	**18-24**				2	**2**	**14**
	25-49	2[11]	2	1	2	**7**	
	Over 49	1		2	2	**5**	
Women	**18-24**		2			**2**	**13**
	25-49	3	2[12]	1	1	**7**	
	Over 49			1	3	**4**	
Total		**6**	**6**	**5**	**10**	**27**	

[10] Age was used here as a representation of generation or social age. Many persons' in Liberia are not aware of their actual age and documentation of this is lacking.

[11] One of the case studies in this category CS007 requested that they were no longer included in the study following analysis and inclusion of their data in the paper presented in chapter 6. They were made aware that this data had already been published and their narrative removed from future analysis, specifically that which is presented in chapter 7.

[12] One case study within this category was also a previous leprosy patient. The participant was selected on the basis that they had recently completed treatment for Buruli Ulcer and therefore is counted in the summary table 3 in this category.

Table 4: Detailed Breakdown of Case Study Participant Characteristics

Case Study Number	Age	Sex	Marital Status	Occupation /Job Role	Educational Level	Disease of Interest/Clinical Manifestation OR Relationship to patient
Maryland County						
CS001						
Illness Narrative	25-49	F	Widow	None	No Education	Buruli Ulcer (arm)
Household Member	Not Available, Interview at Facility					
CS002						
Illness Narrative	25-49	F	Partnered	Market Woman	Attended Primary School	Lymphoedema (Severe, Left Leg)
Household Member	25-49	M	Single	None	Completed Primary School	Brother
Household Member	25-49	M	Partnered	None	Attended Primary School	Brother
CS003						
Illness Narrative	Over 49	M	Widow	None	Noe Education	Lymphoedema (Severe-left leg; moderate-right leg)
Household Member	Over 49	F	Widow	None	No Education	Sister
CS004						
Illness Narrative	25-49	F	Married	None	Attended Primary School	Lymphoedema (moderate-right leg; mild-left leg)
Household Member	25-49	M	Married	Township Commissioner (Local Government)	Attended Secondary School	Husband
CS005						
Illness Narrative	Over 49	F	Widow	None	No Education	Leprosy

Household Member	25-49	M	Married	Farmer	Attended Secondary School	Nephew
CS006						
Illness Narrative	25-49	M	Single	None	Attended Secondary School	Hydrocele
Household Member	25-49	M	Married	Farmer	Attended Secondary School	Brother
CS007: Excluded						
CS008						
Illness Narrative	25-49	M	Married	None	Attended Primary School	Lymphoedema (Severe-right leg)
Household Member	25-49	F	Married	None	No Education	Wife
Nimba County						
CS009						
Illness Narrative	18-25	M	Married	None	No Education	Leprosy (discharged)
Household Member	25-49	F	Married	None	No Education	Wife
CS010						
Illness Narrative	Over 49	M	Single	Farmer	Attended Secondary School	Leprosy (discharged)
Household Member	Unavailable for Interview (Daughter)					
CS011						
Illness Narrative	Over 49	F	Widow	None	No Education	Leprosy (discharged)
Household Member	Over 49	F	Single	None	No Education	Sister
CS012						
Illness Narrative	Over 49	M	Partnered	Night Security	Attended Secondary School	Leprosy (discharged)
Household Member	25-49	F	Single	Farmer	No Education	Daughter
CS013						

Illness Narrative	18-25	F	Partnered	At School	At School	Buruli Ulcer (discharged)
Household Member	25-49	F	Married	Market Woman	No Education	Mother
CS014						
Illness Narrative	25-49	F	Single	None	Attended Secondary School	Onchocerciasis (Blind)
Household Member	Over 49	F	Widow	Farmer	No Education	Mother
CS015						
Illness Narrative	Over 49	M	Married	Farmer	Attended Secondary School	Onchocerciasis (Blind)
Household Member	25-49	F	Married	Farmer	No Education	Wife
CS016: Excluded non-NTD case study, only became apparent during narrative.						
CS017						
Illness Narrative	25-49	F	Single	Fufu Seller	No Education	Buruli Ulcer (discharged) Leprosy (discharged)
Household Member	No Household Member					
CS018						
Illness Narrative (NB: wife of illness narrative CS012)	Over 49	F	Married	None	No Education	Leprosy (discharged)
CS019						
Illness Narrative	25-49	M	Single	Farmer	No Education	Leprosy (on treatment)
CS020						
Illness Narrative	18-25	F	Single	Market Woman	Completed Primary School	Leprosy (on treatment)
CS021						
Illness Narrative	18-25	M	Single	At School	At School	Leprosy (on treatment)
CS022						

Illness Narrative	25-49	F	Partnered	Selling	Attended Primary School	Leprosy (on treatment)
CS023						
Illness Narrative	25-49	M	Partnered	Farmer	No Education	Leprosy (on treatment)
Bong County						
CS024						
Illness Narrative (NB: niece of illness narrative CS025)	18-25	F	Single	Market Woman	Attended Primary School	Buruli Ulcer (on treatment)
CS025						
Illness Narrative	25-49	M	Married	None	Attended Secondary School	Buruli Ulcer (on treatment)
Household Member	25-49	M	Partnered	Contractor	Completed Secondary School	Brother
CS026						
Illness Narrative	25-49	M	Single	Selling Books	Attended Primary School	Buruli Ulcer (on treatment)
Household Member	18-25	F	Single	At School	At School (111th Grade)	Niece
CS027						
Illness Narrative	Over 49	F	Widow	None (retired)	None	Onchocerciasis (Vision Impairment Skin Complications)
Household Member	25-49	M	Partnered	Nurse Aid	Completed Secondary School	Son
CS028						
Illness Narrative	Over 49	M	Married (wife left)	None	Attended Secondary School	Onchocerciasis (Blind)
Household Member	Over 49	F	Widow	None	None	Mother

4.7.5 Case Study Analysis

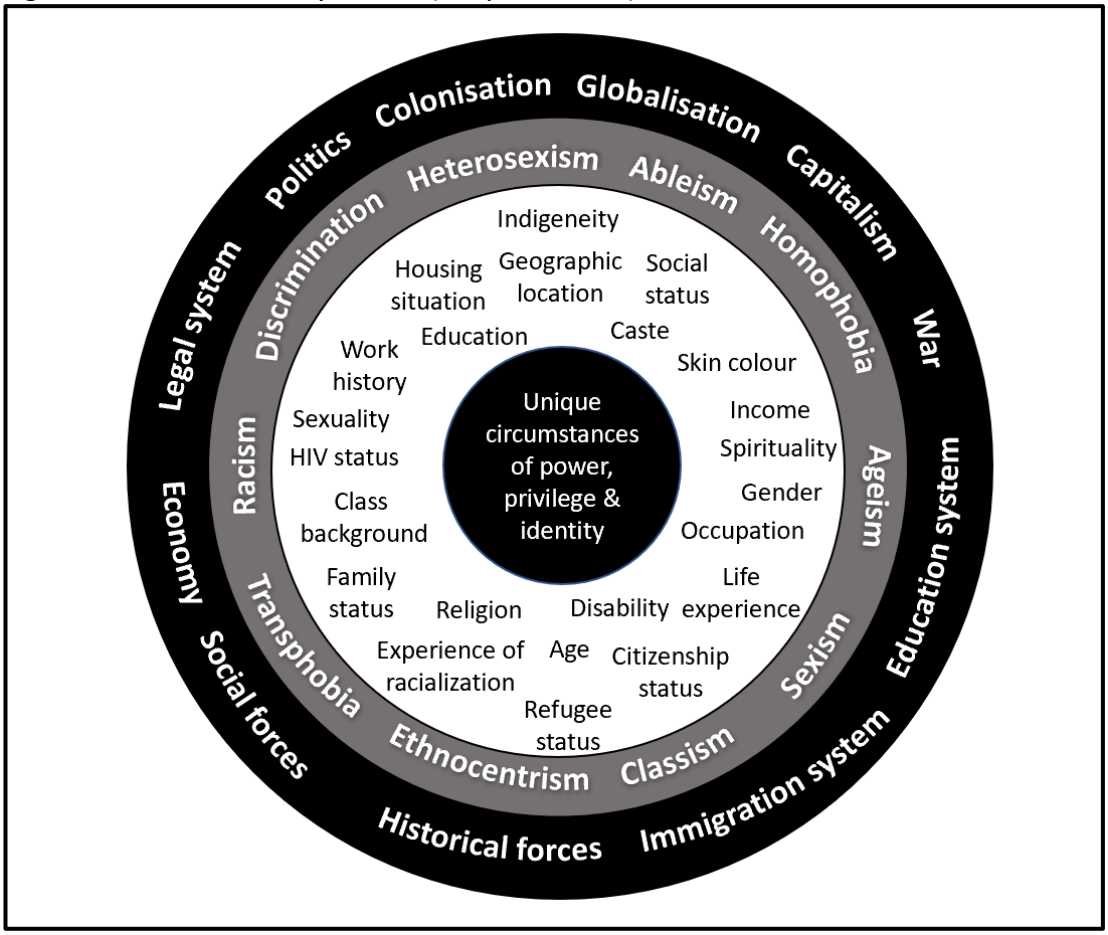
> *'Whether or how a story makes sense seems not so much an analytical question as an experiential one….any analysis seems to depend on an experience that is prior to and always somewhat outside the analysis' (Frank, 2013p361-362)*

Debates surrounding best approaches to both narrative and intersectional analysis resulted in the need for a highly iterative approach to analysis that explored varying options and the integration of multiple analytical approaches. The primary focus throughout analysis was to privilege the voice of the person who is 'ill' and other members within the household and this value was considered in establishing the best path forward within the analysis. Analysis drew on the use of traditional analytical methods including thematic analysis, which requires the '*slicing and dicing'* of data, as well as analytical steps that allowed for the holistic consideration of case studies and stories (Thomas, 2010). Analysis was ongoing throughout the data collection period, this included: critical reflection of emergent issues and themes during the first interaction with participants; re-listening to initial interviews; the design of questions to explore key themes and emergent issues in subsequent interviews with the person affected by NTDs and their household member; and dialogue and debriefing discussions with Gartee. Learning from one case study was frequently applied in asking questions of other participants. Following compilation of the case study set, all interviews were transcribed verbatim. Clarity was provided within transcripts where the translation or phrase in Liberian English was not clear to me, points of clarification were checked with an additional member of the COUNTDOWN team and discussed where necessary.

All transcripts within a case study were then read and a summary of the case study developed (see Appendix 3). During the production of the case study summary, key threads and themes within each narrative were identified and considered in relation to the broader temporal and social context of the narrative. Specific social and temporal factors to be considered were drawn from Simpson (2009) intersectionality wheel, see figure 6, and the contextual understandings developed through key

informant interviews. The key social and temporal factors used within the analysis aligned to key thematic areas described in section 3.6 that emerged as critical themes shaping illness experience within existing literature. From these summaries a very broad coding framework was developed (see Appendix 4) that could be used to explore links and patterns across narratives that could support health systems responses(Pluta et al., 2015). This coding framework was also shaped by key domains within the international classification of functioning, see figure 5, particularly given the studies key focus on the links between chronic disease and disability. The coding framework was then applied to the data using NVIVO 11 software. Data was deliberately coded in large chunks to maintain the flow of narrative where possible. Multiple codes were then drawn together into key themes identified during the summarising and coding process. Charts were developed to also reflect variation in participant gender, generation and disease of interest. Three sets of charts were developed per-theme those that drew on person affected only data; those that drew on household only data; and those that drew on all data within one chart. This allowed for consideration of variation in individual and household experience. Charts were then summarised to develop descriptive and analytical accounts of each theme.

Figure 6: Intersectionality Wheel (Simpson, 2009)



4.8 Objective Three: To elucidate what medical, social and economic strategies would allow for more equitable and effective DMDI for selected NTDs from the perspective of affected individuals, with exploration of how such strategies could be integrated between diseases and within the wider health system.

This objective was met primarily through the combined analysis of key informant interviews, observations documented within my reflexive diary and illness narrative case studies, the process for which is described in sections 4.6.5 and 4.7.5. In addition to collective analysis, recommendations were also generated during dissemination meetings and presentations where I was able to share study findings. The following dissemination activities were completed:

- Feedback discussions and presentations with county health team representatives on completion of data collection in their county.

- Presentation of preliminary findings at NTD programme annual review meetings 2017,2018 and 2019. The 2018 meeting was the mid-point review of the integrated case management plan. This allowed me to contribute to plan adaptations and ongoing development and delivery.
- Presentation of findings during the 2018 and 2019 annual COR-NTD conference in New Orleans and Maryland, which brings together international NTD researchers and programme implementers.
- Presentation of findings during the COUNTDOWN national dissemination meeting in March 2019 that engaged MoH representatives from all departments and representatives of other sectors.
- Ongoing discussion and reflections with the National MoH NTD case management team and implementing support partner (AIM Initiative) to explore what findings mean for policy and practice.

4.9 Ethical Considerations

Ethical approval was granted from the Liverpool School of Tropical Medicine (16-070) and by the University of Liberia, Pacific Institute for Research and Evaluation Institutional Review Board (17-02-024). Necessary approval letters were also sought from the National Ministry of Health and permissions to collect data obtained from Bong, Nimba and Maryland County Health Teams.

I provided Gartee with training on how to take informed consent as part of her one-week qualitative training described in section 4.5. Written informed consent was taken from all participants for key informant interviews and where possible in illness narrative case studies. Where participants were illiterate (which was relatively common due to low levels of literacy across Liberia), or where participants were blind or visually impaired, information sheets and consent forms were read aloud and explained to participants. Participants were then asked to provide a thumb print on the consent form or provide verbal consent which was witnessed by myself and Gartee. Interviews were only audio recorded when consent had been provided. In some cases, participants were hidden within the household or perceived as a

dependent based on their illness and therefore negotiating access to these individuals could be challenging. In two cases, we had to seek permission from the head of the household prior to speaking to the key participant. One of these cases (CS009) was an 18-25-year-old male affected by leprosy, and the other (CS014) a 25-49-year-old female who was blind as a result of onchocerciasis. In both of these cases, affected persons were particularly ostracised and or vulnerable and the rational provided for needing consent from the head of the household described as linked to their protection. In these cases, individual participants were always asked to provide consent and were not coerced to take part based on the decision of the household head. However, this did present an ethical dilemma and it is essential to acknowledge that these relatively powerless individuals may have felt unable to go against the decision of the household head. In both of these cases, we made additional visits to the participant to explain the study purpose and gave additional time for them to contemplate their inclusion in the study. All participants were told of their right to withdraw from the study at any time at no risk of penalty or punishment or impact on their relationship with health centre staff.

Anonymity and confidentiality were critical priorities throughout data collection. All audio files and transcripts were stored separately from consent forms and only the research team had access to files that linked anonymous data codes to participant identity. The position of some of the participants within this study may make their responses identifiable. I have reduced the use of evidence of this nature as far as possible, however where inclusion of the data is essential, I have discussed with the relevant participants that the representation of their opinion is accurate and that they are happy for it to be included within this thesis and associated publications.

The health system is continuously over-stretched in Liberia due to a significant shortage in health workforce. We were therefore flexible in arranging field visits and interviews that involved health personnel. This flexibility or waiting around county health team departments often allowed for deeper contextual understanding of health systems function in Liberia, ultimately strengthening the overall study.

Some of the participants that we interacted with needed medical treatment. One participant had been diagnosed with Buruli ulcer but despite countless attempts to

access medicines, health systems delays had meant she had not yet begun treatment. The NTD focal point (who introduced us to the participant) also felt frustrated at his failed attempts to obtain medicines from the national level. Given the progressive and disabling nature of Buruli ulcer, this was a key ethical dilemma within the study. Following the interview, I decided it was our responsibility to do all we could to get the treatment necessary for this participant. Based on a strong and collaborative relationship with the national NTD team, I was able to ring the national programme co-ordinator (Karsor) and explain the situation to him. He requested that the NTD focal point send a photograph of the ulcer to him immediately so that he could do all that he could to source necessary treatment. The ease of follow up and interaction, resulting in the provision of treatment raises larger questions about my positionality and its use to get a response for a specific patient; however, it felt like the appropriate action to be taken in line with good ethical research practice which states that researchers should have the welfare of the research participant as a goal (beneficence).

Depth of detail within narrative accounts frequently revealed that participants were unaware of the diagnosis or degree of permanency of their condition and significant mental health challenges such as depression and suicidal ideation were often described. The ethical responsibility and dilemma such descriptions presented at times felt insurmountable. I felt a responsibility both to the study participants, to Gartee, and to myself in ensuring appropriate support for all involved. For participants, where I felt their descriptions of severe depression, anxiety or suicide were ongoing rather than historic, I discussed the option of possible support with participants, and where they requested support indicated their vulnerability to the NTD team and or the relevant members of the county health team. Gartee's experience as a nurse and deep understanding of mental health in a Liberian context was essential during these dialogues and interactions; the way she supported and comforted patients was dignified and humane and something from which I learnt a great deal. Following narrative interviews, to ensure that Gartee and I had the necessary space to reflect on participant accounts, we would have lengthy debrief sessions to make decisions about whether we needed to take follow up action. I

would also discuss these experiences again with my supervisors on return to the UK to seek their advice and guidance. Despite these processes, the relative weakness of health system support services for mental health in study locations cannot go unrecognised. In line with beneficence I see it as an ethical imperative to share the findings around mental health that this study has evoked to try and strengthen support services in this area and to contribute toward enhanced social justice for affected persons. I have begun to do this through sharing of findings with: The Carter Center in Liberia (the key mental health implementation support partner); the National Ministry of Health Mental Health and NTD teams; and in a successful application for future funding from the National Institute for Health Research (UK) to begin to develop support interventions in this area in collaboration with the Ministry of Health in Liberia.

4.10 Challenges, Limitations and Trustworthiness

There are several challenges and limitations that arose during the data collection and analysis that need to be considered and mitigated to ensure data quality. Key steps were taken to enhance the trustworthiness of the data collection and analysis process as presented within this section.

The collection of illness narrative data is dependent upon the skill and patience of the research team as well as the willingness and ease of participant monologue. Gartee was new to qualitative research and therefore large amounts of time had to be spent in training her on types of questioning that are useful in such an unstructured method as well as in supporting her to understand the conceptual roots and focus areas of the study to support in asking probing or follow up questions. Gartee's learning process took time and the quality of narrative tended to improve throughout data collection, with some of the earlier narratives taking a focus toward issues unrelated to health and wellbeing, which were directed by Gartee as opposed to the participant. This was compounded in communities where we had to draw on the CDD or CHA as a translator. The majority of CDDs or CHAs were able to complete concurrent translation, this meant that Gartee or I where necessary, could maintain control of questions and follow up questions being asked. In some instances,

translators took it upon themselves to also ask probing or follow up questions. Gartee and I did all that we could to manage this, however, this sometimes resulted in tangents to the narrative thread. It is important to note at this point, that regardless of the overall success of the translation process, some detailed elements of the narrative will have been lost. Pauses in participant monologue to allow for translation may have also detracted from narrative flow. Unfortunately, it was not possible to identify research assistants that had the necessary language skills to support data collection across all three study counties due to the large diversity in languages spoken within Liberia. A decision was made that one research assistant for the whole period would be of better support to methodological consistency than the use of multiple research assistants across counties.

Follow up interviews supported in mitigating against these methodological challenges, with participants frequently expressing gratitude that we had returned as there were multiple things that they had forgotten to tell us. Participant monologue was frequently easier to obtain in follow up interviews than previous. The gap in the process that allowed Gartee and I to review the first narrative together also supported in the development of probing and follow up questions as we were able to discuss key themes and areas that needed further exploration. Finally, although the use of CHAs or CDDs as translators was sometimes problematic, the familiarity of these individuals to participants, particularly in a caring or supportive roll, often supported in building rapport and in establishing trust.

The highly unstructured nature of the method coupled with the fact that many of the people we spoke to had never been asked to share their story before, often presented challenges in encouraging participant monologue. To try and minimise this challenge, we made multiple visits to participants prior to the initial interview to support in establishing trust and rapport. This was also considered in developing the case study approach and was the key rationale for addition of the follow-up interviews. Ideally, we would have made more follow up visits to participants based on the added detail that was frequently provided during the second visit. However, to ensure diversity in case studies resources and time available only one follow up activity was possible. The second interview with case study participants was however

essential, with many participants providing reflection on the therapeutic nature of story sharing, highlighting that time provided between interviews for reflection also allowed them to think of other things that they wanted to share. Cumulatively, multiple visits to participants, sustained interaction through individuals familiar to them, and ongoing review of the findings, contributed to enhancing rapport with participants and in promoting iterative questioning, thus contributing to enhancing the credibility of research findings (Mays and Pope, 2000).

Participant identification was challenging. To find participants we often had to be creative and rely on the tacit knowledge of programme implementers (see section 4.7.2.1), consequently, most participants spoken to within this study were already known to health systems actors or documented within health system records. One of the key challenges with highly stigmatising NTDs is that affected persons are frequently hidden, unknown to or underacknowledged by the health system. This will have shaped the course of their illness experience and consequent narratives. Therefore, narratives from those who have made limited or no contact with the health system are likely to be underrepresented in this study. Furthermore, narratives were only collected in counties where the case management plan is currently being rolled out with support from an implementing partner (AIM International). As such, health systems responses and support services for person's affected are likely to be stronger in these counties. There are many other persons affected by NTDs within Liberia who remain unknown to the health system and who were not included in this study. Identification of some of these individuals would have undoubtably provided alternative illness narratives and was considered in the analysis and interpretation of narrative within this thesis. As yet, I have been unable to share or present my findings to groups of persons affected by these NTDs, which would ultimately contribute to the credibility of study findings, whilst seeking diversity in experience. This is something which I hope to do on future visits to Liberia and in supporting the development of future research projects that can contribute to intervention-based responses to needs identified within this thesis. In an attempt to minimise threats to trustworthiness of this study based on a lack of member checking, I have tried to disseminate and present study learnings to individuals

deeply embedded within a Liberian context as much as possible (see section 4.8) (Mays and Pope, 2000).

One of the NTD focal points that we interacted with throughout the course of this study was keen to engage in every part of the data collection within his county. Such engagement was highly beneficial in the identification of study participants and in navigating county administration systems, however, it presented key challenges when trying to interact with participants on an individual basis. Initially, he insisted on being present for these interactions, which was particularly challenging as they frequently sought to provide 'clarity' on what participants were saying, or by providing their own interpretation of patient experience, particularly where participants were familiar to them. Given that we were particularly interested in capturing the voice of the 'ill' person as opposed to the medical professional this was challenging and particularly off-putting to Gartee who was leading the narrative interview process. To try to mitigate these interruptions, we decided to talk to the focal point about the need for him to not be present during narrative generation and tried to give him other tasks in communities such as supporting to develop sampling frames, so we could identify additional participants. We also made it clear that his opinions were valid to us and arranged a specific time where he could share his thoughts and ideas with us about ways to strengthen the programme as well as reflect on his interactions with persons affected by NTDs.

My initial position as an 'outsider' to the NTD team and many of the key informants who I interviewed, frequently shaped their response to my questions. For example, I often felt like I was being told the official or policy/programme-based response to the questions that I was asking. This was frustrating at points as I could see a disconnect between what I was observing and what people were telling me in interviews. The infancy of the integrated case management policy coupled with passion and commitment of the NTD team to its implementation were also key factors in the desire or demand to present the policy in a positive and successful manner. Over the duration of this PhD project, I felt my position as an 'outsider' in Liberia begin to shift, particularly within the NTD programme team and with those working on chronic disease and disability with whom I frequently interacted on

extended stays in Liberia. The issues that people were willing to share with me, both in formal interview-based settings and in informal discussions changed. People became more critical of the challenges they experienced and willing to suggest ideas of how-to problem solve. There is still likely a filter applied to what is or isn't shared with me; however, I think that many visits to Liberia over a prolonged period and constant dialogue with the NTD programme team have increased the credibility of the understandings of the integrated case management plan presented in this thesis. Finally, I have disseminated my findings to local and international health systems actors, NTD specialists and representatives from other sectors, at several meetings in Liberia and internationally. During these dissemination presentations I have encouraged subject matter experts to challenge findings and recommendations as well as asking for clarity or ideas as to what certain parts of patient experience may mean for health systems responses. Cumulative analysis of my data from across levels of the health system throughout analysis and in delivering these presentations also aided in the triangulation of data sources and study findings. This has supported the trustworthiness of my study findings as well as encouraging critical reflection on the practicability of my recommendations.

4.11 Reflexivity

Continued reflexivity was critical to the design, delivery and analysis of this PhD and consideration of my position as an 'outsider' within Liberia and its influence on knowledge construction imperative(Mays and Pope, 2000, Moser, 2008). Recognition of my role within the research process is also critical to enhance the confirmability of study findings. The role of the researcher in narrative construction and analysis, particularly from a standpoint such as mine (see section 4.2.3), can make the dependability of studies such as this challenging. I have tried to write as detailed account as possible of the methods used within this study, provided clear description of my positionality, as well as capturing key points of reflexivity, in an attempt to be as transparent as possible in my account. I hope that critical reflections such as those presented within this section support to enable judgements of the value of what I have co-produced with participants from my particular standpoint.

My reflexive process and psycho-social processing of some of the narrative accounts shared with me in this thesis is still ongoing and will continue throughout my research journey and work linked to chronic illness and disability. Throughout my PhD journey I have been frequently confronted by issues of power and privilege that result in my continued questioning as to whether I am the person best placed to collect and share the stories of those who I interacted with and how my sharing shapes the way that these stories are told, listened and responded too (England, 1994, Smith, 2014). I have tried to explore some of these dilemmas within the following discussion, which I hope will improve the quality and relevance of this work to the people of Liberia. The key points of similarity and difference within the narrative accounts collected from a diverse range of individuals, support the conceptual saturation of this study, and I hope that together these factors also support the trustworthiness and relevance of this work in other settings.

In 2016, I was part of the Emerging Voices for Global Health Programme, linked to the Health Systems Global Research Symposium in Vancouver. This programme led me to become embedded in the Emerging Voices network, which has resulted in an ongoing and sometimes confrontational exposure to debates around the decolonisation of science. In this context, these debates are centralised around: how 'knowledge' and 'truth' is prioritised and valued within health systems research; challenging the overdominance of 'western ideals'; and in reducing the over-representation of 'white western academics and practitioners' in driving forward academic debate and establishing new research agendas(Goudge, 2003, Lang et al., 2012, Saha, 2019). This has led me to continually question my place (as it should) within the world of health systems and policy research and particularly consider how I present and share my research ideas. Through long discussions with my peers and emerging voices colleagues, I have settled on an approach that prioritises partnership and capacity strengthening in establishing more equitable relationships when conducting global health research. This approach became central to the way that this thesis was carried out and at points meant compromising what I perceived as essential research goals or outputs to ensure the use and relevance of this project. I frequently had conversations with the study team in Liberia to explore how they

perceived the project trajectory, explore their ideas for development of research tools and analysis processes, and in specific relation to the MoH team how useful they thought the findings would be for future intervention design. Granted, given the deep and complex political history of Liberia and an over-reliance on donor priorities, they may have not answered me in an honest or transparent way associating my position with future funding or job opportunities, but this was a key attempt in trying to establish a transparent working relationship.

High levels of aid dependency in Liberia, because of a protracted conflict and recent Ebola epidemic, coupled with my 'whiteness' and 'foreigner' status, often resulted in me being perceived as an expert in all things health systems. This made me feel uncomfortable as a (relatively) young academic with less experience than most of the people I was interacting with, and I frequently tried to position myself within conversations as there to learn about Liberia and the issues under study. Provision of my 'expert' status frequently shaped the ability of study participants to develop and shape solutions to the challenges faced both within the health system and in their everyday lives. When asked questions about what could be done to support people affected by NTDs I was frequently met with a response suggesting *'I don't know what you people have on your mind, so I can't say anything (CS003)'.* This often provoked the need for us to make suggestions of the types of activities or things that could be done to support affected persons to enable us to elicit more reflections from participants. It was infrequent however, that participants or health systems stakeholders would challenge our suggestions (in rare cases they would seek more clarity about what we meant), thus questioning the idea that some recommendations within this thesis are generated through a participatory dialogue that can shape the development of person- centred health systems. I have tried to counter this challenge through the constant exploration and presentation of narrative descriptions that challenge the dominant accounts or understandings presented within this thesis (Hewitt, 2007). Furthermore, as Rose (1997) would suggest, the way in which readers of this thesis and 'listeners' to dissemination presentations choose to interpret and use study findings is outwith my control, thus

challenging my position of authority or power in the development of knowledge as the author of this thesis (Rose, 1997).

My presence at narrative interviews undoubtably shaped the way that participants told their story. Participants often viewed me as there to help or in bringing something that would benefit them. In one extreme case, one participant described that my presence within the household altered the way that their family interacted with them between my visits as they thought I was bringing something they could also benefit from. I found this particularly challenging; my presence had brought reprieve from stigma and discrimination for a short time, but what would happen when I left, and no immediate benefit was brought to the household. I talked this through with Gartee, and other members of the COUNTDOWN team, who were supportive in challenging my ideas that we could 'fix' things for everyone that we interacted with; rather that the process of change in Liberia is far bigger than me or this research study. This was an honest and confrontational interaction but a necessary one in ensuring my transition from a perhaps naïve or inexperienced perspective that it is possible to 'change the world' through a small-scale research study to a renewed sense of responsibility to share our experiences and 'act' where possible. This interaction was relatively early on within my PhD journey, and as a result we decided to spend much more time engaging with participants about the larger purpose of this research, what it was likely to achieve and the direct benefit of their participation. Gartee's role here was critical and the way she was able to relate and explain to participants in a way that made sense to them essential.

Gartee's approach in interviewing and in explaining the purpose of studies to participants was warm and friendly and her position as a Liberian essential in allowing the development of a shared understanding of individual circumstance. I had worried at earlier points in the study that Gartee's position as a nurse and relative 'outsider' would compromise our ability to obtain in-depth narratives that moved beyond participants wanting to share their story as they would with other medical professionals. Gartee's personality in developing rapport with participants was essential and supported in the transition of her role from a relative 'outsider' to more of an 'insider' as a fellow Liberian (Moser, 2008). Participants frequently wanted to

spend time with us outside of the narrative interaction to show us about the way they lived or places of importance within the community; Gartee always made time to engage in these situations and would support participants to explain traditions or customs to me, supporting her transition to becoming more of an 'insider'. The teachings of participants were also of great benefit to me in supporting my understandings of Liberian culture, and I think through taking time to listen, learn and ask questions supported participants in trusting my presence, and thus the types of information that they wanted to share with us.

Throughout the course of this research study, I noticed a visible change in the way the COUNTDOWN team and Gartee interacted with me. Initially the team and Gartee were frequently quiet in meetings and training sessions and often referred to me as their 'boss'. I found this challenging as it was not my intention to be in a position of power and I very much wanted everyone to feel like part of a team. However, I think this description became inevitable based on my geographic origin, educational background and perceived association to provision of financial resources linked to the COUNTDOWN programme. I quickly learnt and observed that in Liberia interactions outside of more 'formal' settings such as in the evenings or over lunch are times when people feel more comfortable to open-up and interact in a more honest way, allowing them to share their ideas and opinions and to do away with the 'boss' status. As a result, I began to use these opportunities to elicit additional thoughts and reflections from the team about the direction of the research study, how they felt about team dynamics and my role and position. Over time, the team began to stop references to my 'boss' status and become more vocal in meetings.

Our first field visit to Maryland certainly helped with a change in my positionality. The journey took over 2 days under challenging road conditions. On arrival in Maryland, the COUNTDOWN team, Gartee, and I then shared a 2- bedroom house for three weeks while conducting data collection. Throughout this time, the team would frequently explain to me how they thought I was 'adaptable' and were amazed that 'someone from the UK would live with them like this'. This period was challenging for me, not only because I was desperately in need of my own space, but because it again led me to constantly question the role of the 'white-western

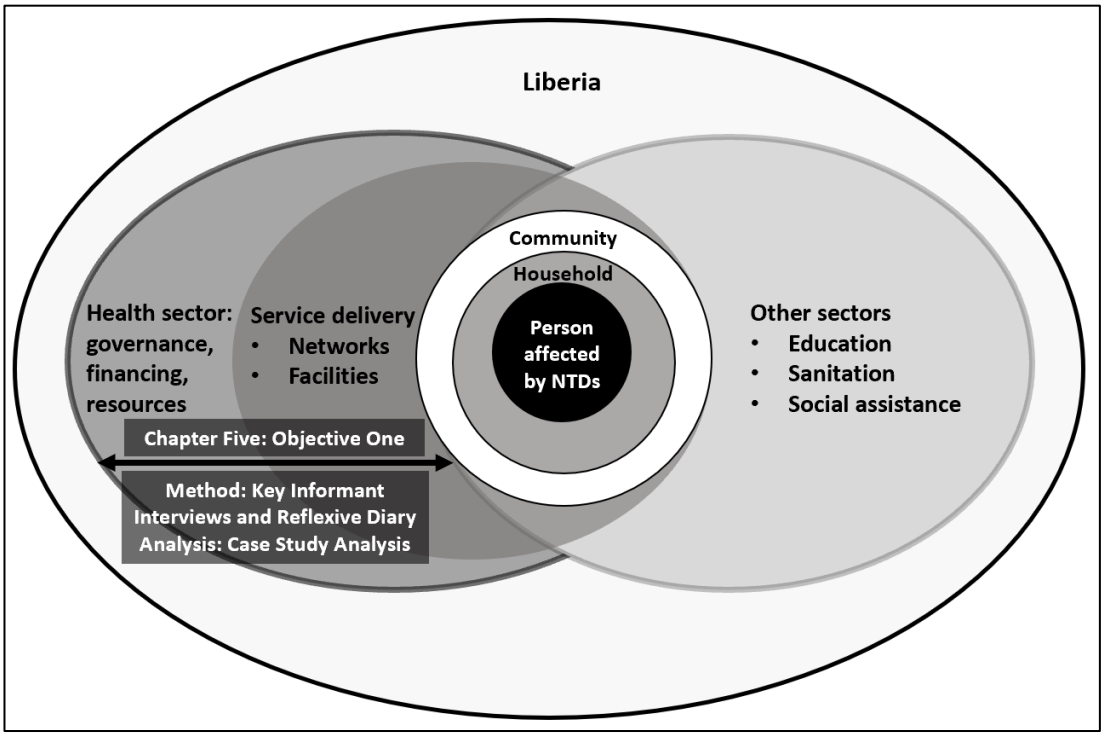
academic' or 'technical expert' whose function is to support research in these settings, often spending limited time-sharing experiences such as this with their teams or going through the lived reality of data collection. I reflected on how this neo-colonial construction of expertise and aid delivery shaped the perceptions that the team had of me and how, despite anyone's best efforts, this invisible dynamic is unlikely to ever be fully removed. However, spending time in this way with the COUNTDOWN team and Gartee in Maryland, Bong and Nimba has changed the way that they interact with me and the way in which they seek clarity or understandings from me about things they have witnessed through our research. Discussions moving forwards have often allowed the team to share personal experiences of conflict and Ebola (not that commonly talked about in Liberia) with me, which has supported my contextual understandings but also showed some level of trust toward me. These interactions and understandings are something which I have tried to think critically about in completing the analysis of the data presented in this thesis, in the sharing of participant stories through various research presentations, and when embarking on new research collaborations.

Chapter 5: Results- Key Informant Interviews

5.1 Chapter Overview

This chapter helps to answer objective one; *to understand the Liberian health system response to chronic disease and disability in specific relationship to onchocerciasis, Buruli ulcer, lymphoedema, hydrocele and leprosy.* Figure 7, shows the relevance of this chapter to the overall study framing, specifically focusing on the intersections between **health sector governance and service delivery**. This allows for deeper understanding of how health systems responses at the national level are influencing the way that services are designed and delivered for the NTDs of focus within this thesis.

Figure 7: Positioning of Chapter 5 within Overall Study Framing



I begin the chapter by outlining the rationale for the development of Liberia's strategic plan for the integrated case management of NTDs, and make a case for the need for synthesis and cross learning between NTD and health systems literature that focuses on the development of integrated, people-centred services. I then draw on a qualitative case study approach that brings together **key informant interviews and observations from my reflexive diary**. Using a case study approach, I consider the

extent to which social relationships influence the successes and failures of aligning NTD programme goals to those of more generalised people-centred health systems. Findings are then presented and discussed in relation to key aspects of people centred health services (putting peoples voices and needs first; people centredness in service delivery; relationships matter: health systems as social institutions; and values drive people centred health systems) to illuminate how varying push and pull factors can facilitate or hinder the alignment of DMDI interventions to generalised health system goals and values.

There is some overlap within this chapter with the recommendations presented in section 8.3. This chapter will be submitted to the *International Health* journal. As described in the manuscript title page on the following page, I led the analysis, conceptualisation and production of this paper which included the production of initial drafts, revisions, finalisation and submission. Other authors were either engaged in data collection (see section 4.5), and/or manuscript reviews in line with their role as supervisors or project partners. RT and ST had a greater role than other authors given their responsibility as PhD supervisors.

Reflections of a journey toward more integrated, people-centred NTD programme delivery: Lessons from Liberia

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Keywords: Disease Management Disability Inclusion, Liberia, Neglected Tropical Diseases, People-centred health systems

Author Contributions:

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GN: data collection, writing-editing

KK: data collection, writing-editing

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5.2 Abstract

Background

Neglected tropical diseases (NTDs) are associated with high levels of morbidity and disability as a result of stigma and social exclusion. Despite associated social causes and consequences, the management of NTDs has been largely biomedical. However, a shift in thinking toward the development of more holistic disease management, disability and inclusion (DMDI) is occurring amongst some sections of the NTD community. Simultaneously, integrated, people-centred health systems are increasingly viewed as essential to ensure the efficient, effective and sustainable attainment of Universal Health Coverage. Currently, there has been minimal consideration of the extent to which the development of holistic DMDI strategies are aligned to and can support the development of people-centred health systems.

Methods

The Liberian NTD programme is at the forefront of trying to establish a more integrated, person-centred approach to the management of NTDs through the development of their 'Integrated Case Management Strategy'(Ministry of Health, 2016). We use a qualitative case study approach to explore how policy and programmatic reform of the NTD programme in Liberia supports systems change to enable the development of integrated people-centred services. Through the use of multiple data sources, including key informant interviews and critical reflection of implementation experience, we consider how far the key aspects of NTD programme reform aligns to the discourse around the development of PCHS and to what extent social relationships influence the successes and failings within the process.

Results and Conclusion

Drawing on Sheikh et al. (2014b) four key aspects of people centred health systems: 1) putting peoples voices and needs first; 2) people centredness in service delivery; 3) relationships matter: health systems as social institutions; and 4) values drive people centred health systems; we illuminate varying push and pull factors that can

facilitate or hinder the alignment of DMDI interventions with the development of people-centred health systems.

5.3 Introduction

Neglected tropical diseases (NTDs) are associated with mortality and high levels of morbidity and disability as a result of stigma and social exclusion (Dean et al., 2019b, Engelman et al., 2016, Hamill et al., 2019, Mieras et al., 2016). The World Health Organizations (WHO) 2020 road map; *'accelerating work to overcome the global impact of neglected tropical diseases'* has prioritised the control, elimination and in some cases eradication of these diseases by 2020, and describes two major strategies by which to achieve such targets(World Health Organization, 2012). The first strategy is innovative and intensified disease management (IDM), which supports disease management through the primary health care system. The second focuses on preventive chemotherapy and transmission control (PCT) through the implementation of large-scale, population based-drug administration, usually termed mass drug administration (MDA)(World Health Organization, 2012). MDA originated from the African Programme for Onchocerciasis Control (APOC), whereby freely donated medicines were distributed by community health volunteers to at risk populations in response to the high levels of visible suffering resulting from river blindness(C.D.I. Study Group, 2010). Despite an early focus on the alleviation of suffering, it is the people affected by NTDs who have arguably become the most forgotten throughout multiple decades of vertical NTD programme delivery focused on MDA[13]. Furthermore, both IDM and PCT have commonly had a heavy biomedical focus, with limited acknowledgement of the social causes and consequences of diseases(Mieras et al., 2016). Given that the majority of these NTDs do not cause death but instead lifelong morbidity and disability, a more holistic approach to the management of NTDs is needed that supports affected persons to negotiate the physical, psychological and social implications(Engelman et al., 2016, Mieras et al., 2016).

People-centred health systems (PCHS) are viewed as essential by many in the health systems community to ensure the efficient, effective and sustainable attainment of Universal Health Coverage (UHC)(Goodwin, 2014, Goodwin, 2016, World Health

[13] Reflections provided my Dr Mwele Malecela during the NNN DMDI working group meeting hosted on Wednesday 18th November 2019, in Liverpool, UK.

Organization, 2014). An essential value in the development of PCHS is a movement away from a system focused on health institutions or disease, to one that focuses on the needs of people, whilst recognising the central importance of relationships and values in driving systems change(Martineau, 2016, Sheikh et al., 2014b). Thus, PCHS favour integration of vertical disease programmes that enables:

> *'health services to take the responsibility to operate specific activities designed to control a health problem…and become one of several channels for the programme to implement its activities, which then become part of the broader package of activities delivered by these multipurpose general health services(Criel et al., 2004pA2)'*

However, within health systems discourses, the relationship between disease control programmes and health services, and the added value of disease control programme integration, has long been debated(Marchal et al., 2011, Criel et al., 2004). Tensions are perceived due to a dichotomy in the underlying value base or objective of disease programmes in comparison to those of integrated and generalised health systems(Criel et al., 1997, Marchal et al., 2011, Criel et al., 2004). Criel et al. (2004), and Marchal et al. (2011) present comparisons of the main elements of disease control and health systems perspectives as shown in Table 5.

Table 5: Core Elements Underpinning Disease Control and Health Systems Perspectives

	Disease Control Programmes	**Generalised Health Care Systems**
Objective	Reduction of burden of disease	Contribute to physical, mental and social well-being
Analysis of health problem	Focus on the presence of disease in population	Focus on people
Decision-making criteria	Evidence of burden of disease and cost-effectiveness	Technical, social and political criteria
Strategic approach to implementation	Short-term actions based on technical solutions and aiming at rapid results	Long term iterative approach aims at protecting people and responding to needs
Concept of 'community'	Intervention target, beneficiaries	Beneficiaries and drivers to which health services are accountable
Concept of 'participation'	Target orientated: needed to fulfil goals	Empowering

Source: Adapted from (Criel et al., 2004, Marchal et al., 2011)

The development of PCHS aligns to the priorities of integrated and generalised health systems. PCHS are often most successful when linked to other efforts or drivers for change, for example in improving health equity(Montenegro et al., 2012), as PCHS demand shifts in accountability away from compliance to government defined targets (bureaucratic accountability) toward systems that enable responsiveness to the needs of service users (external social accountability)(Abimbola et al., 2014, Cleary et al., 2013). Health systems become empowering and users become the stakeholders to whom services are accountable(Criel et al., 2004). Quality of life - as opposed to quality of care - becomes the critical foci of system design, which is driven by holistic needs of communities and social health determinants rather than common epidemiological profiles(Goodwin, 2014). Co-production of services between communities, providers and policy makers is prioritised, supporting a shift from paternalistic care delivery towards enabling systems strengthening and ultimately shaping improved health and wellbeing(Goodwin, 2014, Goodwin, 2016).

Sheikh et al. (2014b), draw this thinking together and outline four core aspects that are central to the development of integrated PCHS: 1) Putting people's voices and

needs first; 2) emphasising people centredness in service delivery; 3) viewing health systems as social institutions; and 4) understanding that values drive people centred health systems (see Box 3)(Sheikh et al., 2014b). To date, a focus on biomedical management of NTDs, driven by the priorities of large pharmaceutical corporations and international donors(Dean et al., 2019a), has dominated academic literature, policy and programming related to NTDs, arguably in opposition to integrated people-centred approaches. Terms such as morbidity management and disability prevention (MMDP) that focus on the cure, prevention or medical management of disease condition reflect this and have translated to little importance being placed on the lived experiences and values of affected populations(Hamill et al., 2019, Mieras et al., 2016), thus compromising the delivery of services that place people at the centre.

The Neglected Tropical Disease NGDO network (NNN) reports a shift in thinking amongst NTD practitioners and associated policy dialogues to focus on strategies that promote the more holistic concept of disease management, disability and inclusion (DMDI) as further described in Box 4(Mieras et al., 2016). Most recently, consultations in the development of the NTD 2030 roadmap have also prioritised the inclusion and development of DMDI interventions with informal discussions suggesting that these will be an essential component in enabling countries to receive their elimination dossier(s) from WHO for specific diseases[14]. The prioritisation of DMDI is aimed at ensuring a full integrated person-centred continuum of care for individuals affected by NTDs, rather than one which is dominated by biomedical approaches and marginalises lived experiences(Mieras et al., 2016).

Criel et al. (2004) suggests that decisions about what and how to integrate disease control programmes is complex. Firstly, it is necessary to understand how desirable integration is, i.e. what is the added value in asking health care systems to add disease focused activities into routine service provision. Secondly, is integration possible based on ability to standardise tasks and the necessity of specialised services. Thirdly, what is the opportunity of integration, i.e. can it help or hinder

[14] Observations from the NNN DMDI working group meeting held in Liverpool on the 18/09/2019.

health systems development(Criel et al., 2004). Despite integration being perceived as desirable for DMDI service delivery, little is currently known about how to effectively shift from NTD programmes that run parallel to routine health service delivery and focus on MDA, to those which focus on integrated, people-centred, longitudinal and lifelong care. Furthermore, in the development of more integrated, people-centred approaches in the response to NTDs, there is currently minimal synthesis of evidence from the broader health systems literature regarding factors that promote such approaches. The aim of this paper is to explore the opportunity and possibility that the development of integrated DMDI strategies for NTDs present for the development of PCHS.

Box 3: Summary of Sheikh, Ranson et al. (2014) Core Aspects of People Centred Health Systems

1) ***Putting People's Voices and Needs First:*** relies on the creation of spaces where individuals and communities can influence the health system that seeks to serve their interests. This may include the establishment of participatory governance mechanisms that challenge power imbalances and hold systems accountable.

2) ***People Centredness in Service Delivery:*** services must be designed and delivered in such a way that places people at the centre as opposed to being structured around disease or for health worker convenience. This relies on services being high-quality, lifelong, accessible and adaptable.

3) ***Relationships Matter: Health Systems as Social Institutions:*** acknowledges that health systems are made up of interconnected actors who interact through a web of complex social, economic and organisational infrastructure which themselves are shaped by societal norms and structures. Effectiveness of systems is intrinsically linked to the strength of relationships and change brought about by actor abilities to navigate these processes.

4) ***Values Drive People Centred Health Systems:*** decision making becomes informed by values of justice, rights, respect and equality and a drive for high quality primary health care. Just as values of systems actors drive decision making, changes within the system shape values.

Literature on health systems strengthening emphasises that systems are highly context dependent and shaped by complex social dynamics(Sheikh et al., 2014b). It

is critical to be able to understand and address such dynamics in the development and implementation of new interventions, as it is these complex and locally constituted relationships that shape how different processes of systems integration occur(Martineau, 2016). Current narratives surrounding the development of integrated, people-centred responses to NTDs are largely framed within global rather than local terms, which is potentially problematic in supporting the development of context specific solutions that are responsive to locally constituted relationships(Martineau, 2016).

The Liberian NTD programme is at the forefront of trying to establish a more integrated, person-centred approach to the management of NTDs through the development of their 'Integrated Case Management Strategy'(Ministry of Health, 2016). This strategy focuses on DMDI for a number of endemic NTDs and their associated morbidities including, Buruli ulcer, lymphoedema, hydrocele, leprosy, and Yaws(Ministry of Health, 2016). Prior to the development and launch of this plan in October 2016, there was no clear DMDI strategy; disease management associated with NTDs was completed on an *ad hoc* basis(Dean et al., 2019b). The context of programme and policy reform in Liberia is therefore used as a case study within this paper. Drawing on the varying experiences of national programme implementers and non-governmental development organisations (NGDO) partners, we explore the creation and roll out of a national integrated DMDI policy for NTDs. We consider how far the key aspects of NTD programme reform aligns to the discourse around the development of PCHS and to what extent social relationships influence the successes and failings within the process.

Box 4: The Origins of Disease Management, Disability and Inclusion

DMDI as a term was developed by the NNN working group for morbidity management in consultation with NTD practitioners within the NNN, based on their tacit knowledge. The purpose of the DMDI approach is to try to foster a more holistic terminology that aligns with interactional approaches to disability and the creation of person-centred health systems. 'Disease management' recognises the need for medical approaches to the morbidity associated with NTDs. 'Disability' is included to emphasise that disability is a consequence of impairment or condition within a particular context and to ensure that social manifestations and other often non-medicalised consequences such as stigma and mental health are not ignored. Finally, 'inclusion' is intended to reflect the need to include people living with the consequence of NTDs in programme design and society more generally (Mieras, Anand at al. 2016).

5.4 Materials and Methods

5.4.1 Study Design

We use a qualitative case study approach to explore how policy and programmatic reform of a vertical NTD programme supports systems change toward the development of people-centred systems and services. Stake (1995) describes our single case study approach as 'instrumental' as it is designed to facilitate thinking within NTD and health systems communities(Stake, 1995) regarding the specific issue of DMDI service integration and the development of PCHS, as opposed to being thought of as 'typical of other cases' (Baxter and Jack, 2008, Stake, 1995). Our case study approach allows for the intense focus on a single phenomenon (policy and programme reform) within a real-life context (Liberia- see Box 5). Through the use of multiple data sources, our exploration acknowledges that 'cases' and contexts are constantly changing and multiple variables and considerations bring complexity to our analyses(Baxter and Jack, 2008, Yin, 1999).

Box 5: Liberia: The Case Study Context

Liberia experienced 14 years of brutal civil conflicts between the periods 1989-1996 and 1999-2003 (Jones et al., 2018; Lee et al., 2011). The civil conflicts have had devastating and long-term impacts on Liberia's economy, infrastructure, health and education systems, with a 'whole generation of Liberians having spent more time at war than in school' (Jones et al., 2018; Lee et al., 2011). Additionally, patchy, vertical foreign aid programmes have historically limited robust primary healthcare coverage and the development of health surveillance systems. However, over the last two decades, Liberia has also undergone periods of bold and rapid policy and systems reform, particularly within the health sector (Jones et al., 2018; Lee et al., 2011). Originating from the creation of The Poverty Reduction Strategy (PRS) 2008-2011, designed to make Liberia a 'model of post-conflict recovery' through a period of rapid sustainable growth, the first large health sector reform was the 2007 National Health Policy (NHP). The NHP introduced Liberia's Basic Package of Health Services (BPHS), established the health pool fund, and prioritised the strengthening of the primary health care system, all with a focus on improving health, health equity and social welfare. The policy oversaw many improvements in health service delivery in Liberia. However, many challenges still remained, including: a rural health delivery gap (at the end of the policy 41% of households (15% urban and 66% rural) had no ready access to a primary health care facility); weak information and data management systems; and under-resourced responses to several chronic conditions including mental health disorders (Lee et al., 2011). The National Health Policy and Plan followed, designed to last for 10 years with a focus on systems reform to effectively and efficiently deliver comprehensive quality health and social welfare services. However, the 2014 to 2016 Ebola epidemic in West Africa had devastating consequences for Liberia's health system and led to a breakdown in trust between communities and service providers, leading to another period of rapid policy reform and reflection (Dean et al., 2019). The 'Investment Plan for Building a Resilient Health System' (2015) became a critical guiding document for the health system and prioritised the integration of vertical disease programmes to support in addressing underlying systems weaknesses. It was during this period of reform, that the NTD programme strategy for 'Integrated Case Management of Neglected Tropical Diseases' was developed.

5.4.2 Data Collection

Data collection took place between December 2016 and December 2018 and involved interviews with key informants and ethnographic observations of meetings at national and international level.

5.4.2.1 Key Informant Interviews

We conducted thirteen individual and one paired semi-structured interview(s) with purposively selected key informants at the national and county level. Key informants were selected due to their role in NTD programme delivery or associated activities and included: Civil Society organisations, NGOs or donor representatives (4); National Ministry of Health staff (6); and members of the county health team (4) from three counties where integrated case management activities are currently being implemented (Bong, Nimba and Maryland). Interviews explored the generation and content of the integrated case management plan; implementation of integrated disease management; and informants' perceptions of key strengths and challenges for disease management, disability and inclusion.

5.4.3 Ethics

Ethical approval was obtained from Liverpool School of Tropical Medicine (16.070) and by the University of Liberia, Pacific Institute for Research and Evaluation Institutional Review Board (17-02-024). Informed consent was taken from all participants.

5.4.4 Data Analysis

We recorded all interviews and transcribed them verbatim. Data was stored and analysed using NVIVO 10. Notes from participant observations were also typed up and where required points of clarity discussed with GN (local field assistant) and the NTD programme team. We analysed all data thematically. Initially we coded grouped data inductively to explore core factors that were related to the interface between NTD programmes and the health system in relation to a) policy development and b) policy or programme implementation. Subsequently, higher level analysis was guided by Sheikh et al. (2014b) core aspects of people centred health systems (See Box 3).

5.4.4.1 Reflexive Diary

To enhance the trustworthiness of key informant interview analysis, this manuscript also draws on experiences of the lead author as documented in a reflexive diary. This included critical reflections from key meetings, discussions and county supervision

activities that were relevant to the development, adaptation and implementation of the integrated case management strategy. Detailed field notes and critical reflections were taken throughout the data collection period.

5.5 Results

Our results are organised into three key sections with emergent themes linked to each sub-section also presented. The first theme, policy development, focuses specifically on policy reform in Liberia in the wake of the Ebola epidemic. The second theme, policy and programme implementation, is concerned with how policy change translates to change within the NTD programme. Finally, theme three, reflections and the road ahead, explores challenges and the way forward for the NTD programme in Liberia as it aims to development more person-centred responses to NTDs.

5.5.1 Policy Development

5.5.1.1 Maximising a Window of Opportunity for Policy and Programme Change

The creation of the integrated case management plan in Liberia was shaped by the cumulation of multiple factors that created a clear window of opportunity for policy and programme change. Informants described how integration of various disease programmes, specifically leprosy and Buruli Ulcer, had been a key national NTD programme priority for many years with the co-implementation, primarily of disease mapping activities, beginning just prior to the Ebola outbreak. Ebola interrupted the progression of such activities and limited the establishment of a fully integrated NTD programme whilst also emphasising clear health systems weaknesses.

In the period immediately after the Ebola outbreak, health systems priorities were observed to change, with a range of actors within the health system coming together to work out the best way forward to be more responsive and resilient to the population's health needs. National health policy reform, including the establishment of the 'Investment Plan for Building a Resilient Health System in Liberia' prioritised a push toward programme integration(Ministry of Health, 2015a).

The merging of programmes, particularly those focused on NTDs requiring case management, was therefore seen as essential '*to save resources and time'* ***(National MoH Staff)***. It was during this time that the NTD programme was able to use adjustments within national policy that prioritised a shift toward vertical programme integration to lobby support and political will from WHO, NGDO partners and the Ministry of Health to make a critical change to NTD policy and programme implementation structures.

> *'prior to Ebola, the voices of the Ministry of Health were absent in designing programmes. No funding was available for case management and so the MoH had very little say in policy and programme design. Following Ebola, we were motivated by access and trying to improve access to case management through the health system…we wanted to move away from a disease specific focus and reduce inequities…with vertical disease programmes, for example for leprosy, some people can access everything…whereas others can't access anything. It seemed like a skewed way of providing development aid'* ***(NGDO Partner Representative)***

NGDO partners who were engaged in the process also described the need to prioritise the viewpoint of Liberian NTD programme staff and other health systems actors with a key focus of policy reform on '*capacity strengthening of the system'* and a hope that the development of the new strategy would '*minimise the disease focus of NTD programmes and emphasise people'* ***(NGDO Partner Representative).*** Informants emphasized the importance of '*designing the integrated case management plan around the four pillars of the existing NTD master plan to encourage support [for programme and policy reform] from WHO'* ***(National MoH Staff)*** as it was a policy or programme format with which they were familiar.

5.5.1.2 Prioritising the View of Affected Persons

Programme implementers from all levels of the health system were described as key in shaping the way that the integrated case management policy was designed, developed and implemented. However, no consensus was reached on the

engagement of involving persons affected by NTDs in programme design and review meetings and they were therefore excluded.

Despite this, it was apparent from interactions with multiple programme implementers that care for the improved health and wellbeing of people affected by NTDs was at the forefront of their efforts and decision making. For example, we observed that some programme implementers would pay from their own pockets for surgical costs, school fees, food and transportation of affected persons. Reflections from key informants also emphasised a desire for a change in focus away from the biomedical construction of disease and associated interventions toward more holistic responses that aligned to their value base and experiences. For example, many informants described feeling like they needed to expand service delivery to include the provision of psycho-social support. However, they felt restricted to be able to do this within the parameters of a fragile health system when they had limited evidence of what would work and where they should target resources. Many described that day to day interaction with affected persons made decisions about what should or shouldn't be included within integrated programme delivery more challenging. Implementers felt compromised in their attempts to establish an integrated programme that worked, whilst still understanding the broader needs of people affected as addressing everything at once felt '*too big'*.

> *'psycho-social elements aren't included at the moment…but it becomes a real wrestle. One reason why integrated case management is not being implemented and adopted by the NTD community is because it feels so big…livelihoods…psycho-social support…we lose the person at the beginning who really just wants to give the pill for these diseases…we had to have an element of compromise…think through what can we do that will have the best impact…' (National MoH Staff).*

> *'I had a case right here in Monrovia. I was called to go and confirm whether this client is a confirm lymphoedema. And when I got there a young girl 26 years got this lymphoedema leg and I talk to her it*

was confirmed that lymphoedema. We taught her to take care of the lymphoedema leg…You wouldn't believe this girl was bold to express her heart that she is too young to live with condition…We taught her exercise what to do to reduce for some of the fluid to go back. And then she said with all of that I cannot live like this all of my life. She said it, she said she is going to take her life. She wants to take her life. Right there I realized that mental complication it has. It is stigmatization because she doesn't move around. I started to understand what about those other cases that are around they are going through the same thing. So, I immediately came and I went through the mental health department and I say look I got a case you guys have to get involve this is the situation, this is a declaration. So, you guys have to take it up from here' (National MoH Staff).

Consequently, long discussions with programme staff often revealed personal distress based on multiple interactions with affected persons who they felt they could not support adequately.

'Because you will see somebody just sitting…depression…you will become depressed…I notice some of them may even want to commit suicide if you don't have a good family background to talk to you…talking to you they will [shy] away from you, we need support for that' ***(County MoH Staff).***

5.5.2 Policy and Programme Implementation: as strong as the system you represent

All were committed to case management being '*part of the regular health service delivery system of the country'* ***(National MoH Staff)*** and described seeking to maximise avenues for integration, which was often highlighted as easier at lower levels of the health system. Informants described some parts of integrated implementation working well whereas others were seen to be limited. Many emphasised that earlier case detection by community health assistants was working

particularly well, due to integrated training, supervision and motivation processes that were aligned to the community health division's policy and programme delivery(Ministry of Health, 2015b).

> *'unlike the past where we used to go out to actively find cases…There is a curriculum formulated to train…community health assistants, and we train the community health surveillance supervisor which is CHSS in all medical related cases. The curriculum was developed by the community health department and the NTD department'* ***(National MoH Staff)****.*

This was thought to be further enhanced by the programme's ability to fulfil a motivation gap for some community health volunteers through the introduction of the active case search incentive policy, whereby community health volunteers (those not currently formally incentivised by the health system) receive 5USD per target NTD case identified and confirmed. This strategy was designed to reduce the demotivation of community health volunteers who are not part of the national community health assistant (CHA) programme that provides 70USD per month motivation to CHAs who have undergone a four-month training programme(Ministry of Health, 2015b).

> *'We have introduced another method called active case search incentive base and it is really for the community health volunteers…from our experience some of them were left out of the community health assistant programme so they are like demotivated and you don't find the community health assistants in all of the communities…So we communicated with the focal points and told them to inform the community health division that every case confirm gets 5 dollars* ***(National MoH Staff)****'.*

Operational integration at the county level was also described as having been relatively straightforward, two-monthly supportive supervision visits from national programme staff to the county level every had enabled the addition of NTDs as an agenda item within weekly county medical meetings. However, it was observed that

this process was smoother in some counties than others, often dependent on the capacity of the county level NTD focal point and the personal relationship between this post and the national NTD team. Integration of the multiple indicators necessary for the effective inclusion of various NTDs within health monitoring and information systems was described as being a more laborious but an essential process to enable the NTD programme to become part of routine county planning activities. Additionally, one of the biggest challenges in establishing integrated service delivery, was described as the supply chain, with many implementers asking *'how do you put something into something that is already broken?'* ***(National MoH Staff).*** This was particularly problematic for many programme implementers who found it challenging that *'we are creating the demand and we don't have the drugs. We don't have the medical supply. So, in order to mitigate that we must have the drugs'* ***(National MoH Staff).***

> *'The challenges are that some of them are lacking of this support, lacking of drugs, sometimes the drugs are not on time… counties don't have the capacity to procure easily, so its national, national should be able to purchase more drugs'* ***(County MoH Staff).***

5.5.3 Reflections and the road ahead: Challenging deep routed verticalization, disease silos and donor control

Despite being presented with a clear window of opportunity for change in policy; programmatic change aimed at achieving person centred practice was viewed as more challenging. Decisions about which diseases to include as part of integrated case management approaches appeared to be based on a bio-medical view of disease condition and the historic dichotomy between PCT and IDM diseases, with specific focus on addressing 'reversible' NTD associated morbidity. However, over the duration of the study this viewpoint began to shift, with programme implementers becoming increasingly reflective about the inclusion of additional disease conditions and the need to link with other sectors to address wider support needs of affected persons.

'I want to believe initially we are looking at conditions that are with a burden, onchocerciasis is one of the burden conditions, but we focused on conditions that we could respond to and bring relief to the client. Like for onchocerciasis once you have gone blind it is difficult like that particular condition. For example, with hydrocele you can do the correction. With Buruli ulcer it can be some level of correction. With lymphoedema stage one if it is diagnosed early you can interrupt the progression. But when you diagnose at a later stage definitely you cannot help the situation. It is just to give some home base health care and health education. I want to believe that in the nearby future onchocerciasis will be included because it causes disadvantages once you cannot see' ***(National MoH Staff)***

Funding of integrated approaches was however the most critical barrier to effective implementation of integrated programme delivery. The funding problem was described as two-fold: 1) the long term and deep reliance on donor funding for health service delivery by the government of Liberia limits the availability of flexible funding; and 2) the ongoing funding prioritisation of donors and NGDO partners toward specific disease conditions. Informants described the resultant precarious nature of integrated programme delivery and the additional workload, stress and ongoing negotiation that such structures enforced on the national programme team was frequently observed. Many described that a change to funding flows and partnership approaches was essential to allow for the sustainability of integrated approaches.

'The challenges there is that we have only one partner that is actually supporting and limited funding from government to support these programmes…so most of the funding that come is through the partner so those are the challenges that are actually face with the program' ***(County MoH Staff)***

Some NGDO partners described that there is limited opportunity for national NTD programmes to provide feedback to international donors regarding the rigidity of funding flows and their associated impacts on programme responses. This limits the

ability of NGDO partners to work with programmes in a way that is mutually responsive to national priorities and can compromise the development of equitable partnerships between NGDO partners and national programmes. Furthermore, where NGDO partners are unwilling or unable to collaborate effectively to facilitate integrated approaches and move outside of disease silos, this was observed to be likely to limit progression toward integrated service delivery.

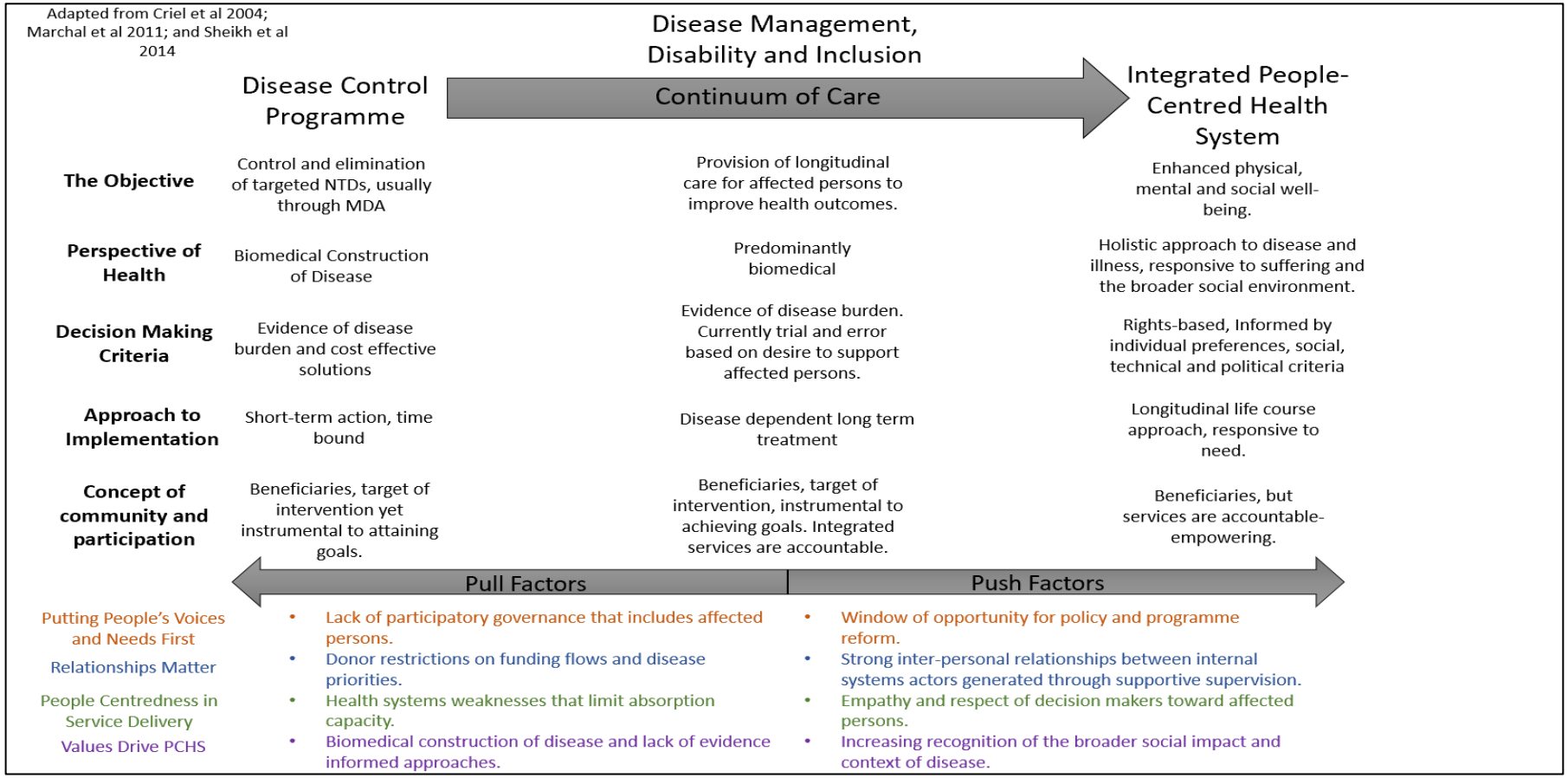
> *'the way things are structured internationally is the biggest reason these programmes have been implemented vertically for such a long time…Funding can be a problem, disease focused funding can be the most frustrating thing…it doesn't really focus on the human…health workers end up having to go and do one thing for five days and then another thing for the next five days, just because we [NGDO partners] aren't willing to work together…there is such a missed opportunity for people to work together. NTD programmes should be given more opportunities to report back…there is a lack of reflection by partners on the impact their own goals and priorities have…could NTD programmes come together to present a framework for good partnership agreement…we shouldn't be ignorant to the fact that there is a co-dependency between NTD programmes and donors…Getting people to leave their disease silos is challenging…I don't know how many more generations of leprosy experts we will need…but hopefully not that many…you win some you lose some…some people are open to new approaches…others are not'* ***(NGDO Partner).***

5.6 Discussion

This article aims to consider the extent to which NTD policy and programme reform can contribute toward the development of integrated PCHS through the alignment of value bases and core principles. The findings above have explored the interface between the health system and NTD policy and programme reform in relation to

DMDI in Liberia. Drawing on the core elements of disease control programmes and integrated generalised health systems presented in Table 5 and adapting them to be of relevance to NTD programming in Liberia, we suggest that DMDI serves as a bridge between NTD programmes conceptualised around disease control and the development of more integrated PCHS(Criel et al., 1997, Marchal et al., 2011) (Figure 8). Our findings illuminate multiple push and pull factors that can facilitate or hinder the alignment of DMDI interventions to the development of PCHS. Within our discussion we consider these push and pull factors in relation to Sheikh et al. (2014b) four key aspects of PCHS (Box 3). The coloured text at the bottom of Figure 8 refers to these cross-cutting issues discussed in each sub-section.

Figure 8: Disease Management, Disability, and Inclusion as a Bridge in Supporting a Transition from Disease Control Programmes to Integrated, People-Centred Health Systems



5.6.1 Putting People's Voices and Needs First

A central tenant of putting people's voices and needs first is the way in which health systems are governed(Abimbola et al., 2014, Sheikh et al., 2014b). Effective approaches to systems governance require consideration of the roles and relations of all systems actors including international NGDO partners and affected persons, not just national governments(Abimbola et al., 2014). Multiple accountability relationships exist within NTD programme governance (international NGDOs and donors to national government; and national government to affected people) that need to adapt to promote the development of person-centred approaches, these relationships are discussed in turn in this sub-section.

Within our study, we found that the 'window of opportunity' or '**push'** for the development of an integrated PCHS in Liberia, presented a critical moment for national actors to hold international NGDO partners more accountable to the provision of an NTD service that responded to their needs and priorities. This saw a long-awaited shift in the core programme objective of the Liberian NTD programme away from a sole focus on the control and elimination of NTDs, to an equally important focus on disease and health systems integration for the provision of longitudinal care for affected populations, a core value of people centred services(Ferrer et al., 2014). Thus, following a moment of health system crisis, the Liberian NTD team was able to carefully navigate deep routed and historical bureaucratic accountability of the national system (toward international targets and priorities due to chronic aid dependency(Nabyonga-Orem et al., 2016), and shape the redirection of their programme toward more person-centred approaches. Capacity strengthening activities that enable a clear role and function of national actors in health governance and priority setting have been described as essential in establishing PCHS(Sheikh et al., 2014a, Sheikh et al., 2014b). Our study findings support this, and highlights the need for a key moment of reflection for the NTD community as we strive to establish person-centred approaches to DMDI. We must consider how to support the full and equitable participation of national systems actors in international agenda setting, and support the adaptation of international agendas to local contexts.

Despite these achievements at the national level, at lower levels of the health system true participation in decision making by affected persons represented a **'pull'** for NTD programme implementers toward disease control centric approaches that see beneficiaries as the (passive) target of health interventions(Marchal et al., 2011). Participatory governance is essential within PCHS(Abimbola et al., 2014) to improve equity and ensure that those with the greatest health needs have the best ability to be able to direct resources (Sheikh et al., 2014b) and there is increasing recognition of the capability of beneficiaries to contribute toward effective priority setting and governance processes(Abimbola et al., 2014, Molyneux et al., 2012) By failing to incorporate mechanisms for these contributions, the NTD programme limits advancement toward a person-centred focus. The use of patient advocates to support the participation of affected persons in priority setting and resource mobilisation is increasingly prioritised within the NTD community through networks such as NNN (Hamill et al., 2019, Tora et al., 2018, Van Brakel and Lusli, 2017). However, our results suggest that a critical challenge remains as to ensure that these actors are given a seat at the table in national policy and programme reform. Limited active engagement of affected persons at national and sub-national levels perpetuate paternalistic approaches to care delivery(Goodwin, 2016), which can hinder quality care experiences and associated quality of life for individuals and communities(Starfield, 2011). Supporting the health system to understand the problems of people affected by NTDs from their own vantage point is a key and critical step in supporting health practitioners and policy implementers to design strategies that enable the delivery of high-quality care(Starfield, 2011).

5.6.2 Relationships Matter: Health Systems as Social Institutions

As is described in the PCHS literature(Gilson, 2003), our findings emphasise the role of trust and ability of national programme staff to manage relationships with external (NGDO partners) and internal health systems actors was critical in shaping how far systems could respond and adapt. For example, inter-personal relationships mattered at implementation levels of the health system where integration of service delivery seemed most permissible. Supportive supervision that established effective working relationships with county health teams enabled national actors to be

responsive to the priorities of staff who are the backbone of NTD service delivery, this was seen to be an essential factor in supporting a '**push**' toward the development of PCHS(Namakula et al., 2014). However, regardless of the strengths of these relationships and the ability of programme actors to lobby political will and shape the generation of a new NTD programme vision in Liberia, restrictions within NGDO funding flows were still observed to stall integrated programme delivery. Donor restrictions currently render some partners unable to move outside of disease specific funding silos, thus reinforcing a **'pull'** toward disease or issue centric service delivery(Marchal et al., 2011, Ortu and Williams, 2017). This limits the responsiveness of NGDO partners and programmes to national health systems priorities and stalls the proposed paradigm shift within the NTD community toward more person-centred approaches. Furthermore, rigid funding flows can limit the ability of national programme implementers to fulfil their leadership and innovation potential as they are held accountable to the implementation parameters of international organisations who are frequently governed by a one size fits all approach(Dean et al., 2016).

5.6.3 People Centredness in Service Delivery

Chronic programme verticalization, that has led to the establishment of parallel NTD programmes, shaped by the priorities of international disease experts and funding bodies(Marchal et al., 2011, Ortu and Williams, 2017), contributed to multiple '**pull'** factors which limit the ability of service delivery to become fully people-centred. Health systems strengthening has seldom been prioritised by the NTD community based on the rationale that NTD programmes reach areas where there have been previous health systems failings and so reliance on community resourcefulness is essential (Marchal et al., 2011). Parallel provision of NTD services has therefore failed to support and address systems weaknesses, thus limiting the absorptive capacity of an already overburdened health system(Marchal et al., 2011). For example, as is the case in Liberia, weak supply chains and scarce human resources often render systems unable to respond to the needs of affected persons at primary or secondary level due to an absence of medicines and psycho-social support services. Immediate and

longitudinal support becomes compromised and the provision of continuous support for affected persons difficult(Starfield, 2011).

Engagement with community health structures is essential to improve interconnectedness between service users and providers and is critically important for improving external accountability of the health system(Cleary et al., 2013). However, it is important to reflect on how this engagement may contribute to or undermine the people-centredness of service delivery. Incentivisation of health workers based on disease case finding reinforces the important surveillance element of their role, but can be seen as at odds with ensuring longitudinal person-centred care(Ferrer et al., 2014). Furthermore, when effectiveness is measured based on disease identification count, equity of service delivery can become compromised and or distorted(Starfield, 2011). Thus, a critical dilemma for any vertical disease programme hoping to support the strengthening of PCHS is how best to support and motivate community health volunteers when they are not adequately or equitably supported within the generalised health system. Establishing quality measures for performance based financing within DMDI programmes that extend beyond case detection could support in the development of a more comprehensive service(Starfield, 2011). Community based comprehensive services should also seek to move beyond patient or disease centred interactions toward approaches that see the person as a whole(Starfield, 2011). Programme implementers undoubtably evidenced empathy toward the holistic needs of affected persons as a key **'push'** factor toward people-centred approaches. However, this is likely to be an ongoing and key test for the NTD community as a shift in focus away from disease challenges their unit of identity.

5.6.4 Values Drive People Centred Health Systems

Perhaps the strongest principle within the development of PCHS is that values are critical and important drivers within health systems reform(Sheikh et al., 2014b). Justice and a focus on people - not diseases - are a key principle underlying the proposed paradigm shift within the NTD community(Mieras et al., 2016) and the main reason sighted for the increased inclusion of DMDI within the NTD 2030 roadmap. Care for and a desire to support people affected by NTDs were

unquestionably at the centre of key informants' motivation for the case management strategies development in Liberia and represent a key **'push'** factor toward person-centred response. However, we found that NTD programme delivery in Liberia is still orientated or **'pulled'** toward diseases and patients. In making a shift toward the development of integrated person-centred services, a key and ongoing challenge for the NTD community emerges in terms of adjustment from bio-medical constructs of disease prevention, diagnosis and treatment to consider the holistic needs of affected persons and their families. Our study showed increasing recognition amongst programme implementers of the broader social impacts of NTDs, specifically in relation to mental ill-health. However, the challenges implementers faced in having the resources or knowledge to respond emphasises that there is a need for further evidence generation on how to make best use of scarce resources to support in systems strengthening whilst meeting the holistic needs of affected persons.

5.6.5 Study Limitations

We have only considered policy and programme reform from the perspective of key decision makers at national and county level within this paper. Engagement with stakeholders at lower systems levels, for example, facility staff and community health workers, who are often at the interface of implementing such reforms, would have provided useful and additional critical insights and should be considered as an area of future research. We have not explored the perspectives of people affected by NTDs in this manuscript; however these insights are essential, and are prioritised within other publications from the same study (Dean et al., 2019b). Reflections on this process from other countries may have further supported the generalisability of these findings. However, we used a case study methodology as an instrument to facilitate thinking within the NTD and health systems community, rather than arguing that Liberia's situation is representative of all countries embarking on the development of more integrated people-centred DMDI service delivery.

5.7 Conclusion

The case of Liberia illustrates the opportunities and challenges in implementing a policy and programme shift towards integrated PCHS within NTD programme reform. Assessing policy and practice against Sheikh et al. (2014b) core pillars of PCHS should be considered by the NTD community as they seek to contribute to the development of PCHS through the provision of integrated DMDI interventions.

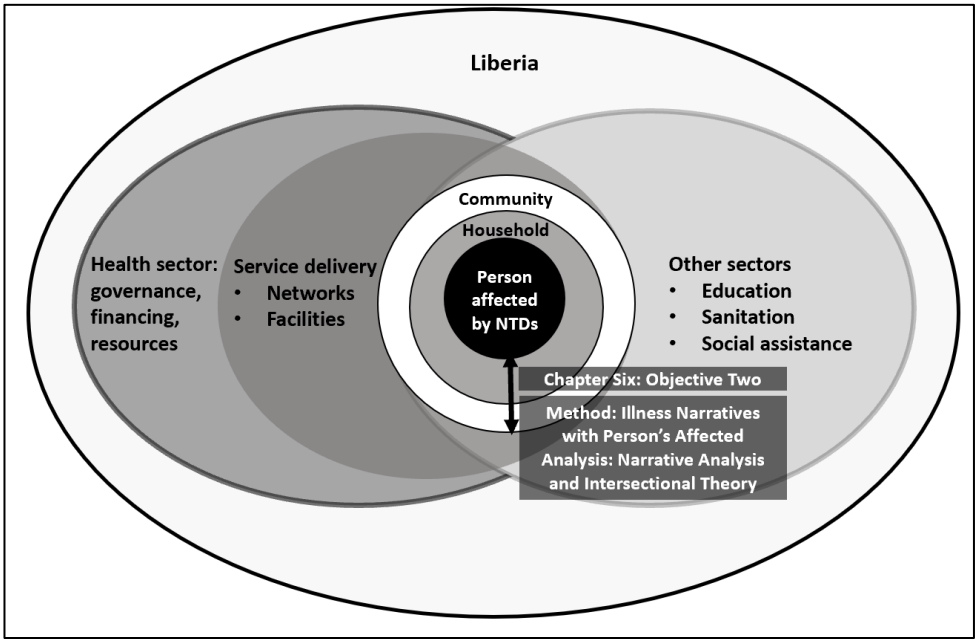
Chapter 6 Results: Narratives of Affected Persons

6.1 Chapter Overview

Within this chapter I draw on narrative analysis using Frank (1995) narrative types and intersectional theory, to contribute to answering **Objective 2: *to understand individual experience of living with one or more of selected NTDs from the perspective of affected individuals and members of their household with a focus on how this varies by differing axes of inequity such as age and gender*.** Figure 9 emphasises the relevance of this chapter within the overall thesis framing. Specifically, it puts affected persons and members of their household at the centre to consider necessary service delivery responses. Specifically, it prioritises the use and analysis of **illness narratives** by drawing on both narrative and intersectional theory to consider individual experiences as well as variations based on factors such as age and gender which contribute toward the construction of individual identities. I begin the chapter by providing theoretical underpinnings relevant to this manuscript, before moving on to detail the rational for the specific methods used. The results are presented thematically in relation to Frank's narrative types, before the discussion considers what this means for health systems responses.

This chapter is published within *PLoS NTDs(Dean et al., 2019b).* As described in the manuscript title page, I led the analysis, conceptualisation and production of this paper which included the production of initial drafts, revisions, finalisation and submission. Other authors were either engaged in data collection (see section 4.5), and/or manuscript reviews in line with their role as supervisors or project partners. RT and ST had a greater role than other authors given their responsibility as PhD supervisors.

Figure 9: Positioning of Chapter 6 within Overall Study Framing



Neglected Tropical Disease as a 'Biographical Disruption': Listening to the Narratives of Affected Persons to Develop Integrated People Centred Care in Liberia

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6.2 Abstract

Background

Integrated disease management, disability and inclusion (DMDI) for NTDs is increasingly prioritised. There is limited evidence on the effectiveness of integrated DMDI from the perspective of affected individuals and how this varies by differing axes of inequality such as age, gender, and disability. We used narrative methods to consider how individuals' unique positions of power and privilege shaped their illness experience, to elucidate what practical and feasible steps could support integrated DMDI in Liberia and beyond.

Methods

We purposively selected 27 participants affected by the clinical manifestations of lymphatic filariasis, leprosy, Buruli Ulcer, and onchocerciasis from three counties in Liberia to take part in illness narrative interviews. Participants were selected to ensure maximum variation in age, gender and clinical manifestation. Narrative analysis was grounded within feminist intersectional theory.

Findings

For all participants, chronic illness, morbidity and disability associated with NTDs represented a key moment of 'biographical disruption' triggering the commencement of a restitution narrative. Complex health seeking pathways, aetiologies and medical syncretism meant that adoption of the 'sick role' was initially acceptable, but when the reality of permanency of condition was identified, a transition to periods of chaos and significant psycho-social difficulty occurred. An intersectional lens emphasises how biographical disruption is mediated by intersecting social processes. Gender, generation, and disability were all dominant axes of social inequity shaping experience.

Significance

This is one of the first studies to use narrative approaches to interrogate experience of chronic disabling conditions within LMICs and is the only study to apply such an analysis to NTDs. The emotive power of narrative should be utilised to influence the

value base of policy makers to ensure that DMDI strategies respond holistically to the needs of the most marginalised, thus contributing to more equitable people-centred care.

6.3 Author Summary

We used narrative methods to consider how individuals' unique positions of power and privilege shaped their illness experience, to explore what practical and feasible steps could support neglected tropical disease (NTDs) programmes to respond to patient need in Liberia and beyond. We asked 27 people living with NTDs (including lymphatic filariasis, leprosy, Buruli Ulcer, and onchocerciasis) to tell us about their experiences. We used narrative analysis with feminist intersectional theory, that allows for consideration of how things such as age, gender and disability interact, to interrogate participant experience. For all participants, morbidity and disability associated with NTDs created upheaval in their lives. Complex health seeking pathways meant that it was socially acceptable for participants to have experienced initial sickness, however as their illness became more permanent, participants described significant negative impacts on their mental-wellbeing, including depression, anxiety and suicide. This is one of the first studies to use narrative approaches to explore experience of chronic disabling conditions within LMICs and is the only study to apply such an analysis to NTDs. The emotive power of narrative should be utilised to influence the value base of policy makers to ensure that NTD programmes respond to all the needs of the most marginalised.

6.4 Introduction

For many people with Neglected Tropical Diseases (NTDs), particularly those requiring case management, their condition is highly visible and significantly contributes to morbidity and disability because of the range of physical impairments, associated stigma and social exclusion(Engelman et al., 2016, Mieras et al., 2016). Delayed diagnosis and disease progression cause greater and largely irreversible physical impairment; and alternative treatment is sought from outside the health system, often with catastrophic economic and social consequences(John et al., 2010, Rao et al., 1996, Rathgeber and Vlassoff, 1993, Reidpath et al., 2011, Tolhurst et al., 2002, Try, 2006). However, disruption to individual lives because of morbidity and chronicity associated with many NTDs is seldom prioritised or discussed due to a historic focus on the control and elimination of disease using mass preventive chemotherapy(Mieras et al., 2016). Additionally, when offered, management of NTD associated morbidity has been highly medicalised with a focus on restoring sight or reducing physical impairment with less consideration of the social and mental impact of these diseases and how this is influenced by inequities such as gender, age, geography and poverty(Mieras et al., 2016, Theobald et al., 2017).

Integrated management of NTDs, defined as the implementation of activities targeting two or more diseases at the same time and in the same communities, has recently been proposed as a key solution to these challenges, however there is limited evidence on the effectiveness of these approaches from the perspective of affected individuals(Engelman et al., 2016, Hay, 2016, Mitjà et al., 2017). Integrated management also seeks to expand the sole focus on the medical management of disease to consider more holistic approaches that focus on disease management, disability and inclusion (DMDI)(Mieras et al., 2016). Simultaneously, within health systems strengthening discourses, the development of integrated, people-centred systems is increasingly emphasised; these put individuals and communities rather than diseases at the centre of health systems strengthening activities and seek to empower people to take charge of their own health(World Health Organisation, 2015).

In establishing DMDI strategies that are aligned to people-centred health systems it is important to understand from affected people what they perceive to be important in relation to DMDI and how this varies by differing axes of inequality such as age, gender, stage of disease, and experience of disability. Through in-depth exploration of narratives of affected persons, we hope to elucidate what practical and feasible steps could be put in place to allow for integrated DMDI that can contribute toward the development of more integrated, people-centred health systems in Liberia and beyond.

NTDs frequently affect the most poor, vulnerable and marginalised and disease burden is highest in areas where health systems are the most fragile and under-resourced, predominantly in sub-Saharan Africa(Engelman et al., 2016). Liberia has a unique and complex socio-political history through which a nexus of factors including slavery, colonisation, civil war, extreme gender-based violence and aid-dependency have woven together to create a context (for many) of long-term oppression and suffering. It is historical oppressions such as these that have resulted in a weak and often ill-functioning health system which, when coupled with extreme poverty, has rendered the impact of national crises (e.g. Ebola) and personal crises (e.g. disease and/or illness) more severe. Most recently, following the Ebola (EVD) epidemic in Liberia, the 'Investment Plan for Building a Resilient Health System' prioritised the integration of vertical disease programmes(Ministry of Health, 2015a) to try to respond to ongoing weaknesses within the health system. During this most recent post crisis period, Liberia became one of the first countries in the world to develop, adopt and begin implementation of a national integrated approach to the management of NTDs, specifically those requiring case management (lymphatic filariasis (LF), leprosy, BU and yaws). The approach seeks to address issues of equity and effectiveness previously neglected through fragmented approaches(Ministry of Health, 2016), whilst contributing to health systems strengthening. Despite this significant step, there is still minimal evidence on the perspectives of individuals living with NTDs in terms of what the plan should include and how it should be implemented in Liberia. As the Ministry of Health moves towards completion of the first revisions of the integrated case management plan following its first phase of

implementation, this presents a unique opportunity to consider the perspectives of affected individuals, whilst sharing learning with other countries with people with NTD related morbidities.

We sought to move away from the categorisation of individuals based on disease and explore potential synergies in illness experience between varying NTDs from the perspective of people affected. We use feminist intersectionality theory as a key analytical lens to consider how individuals' unique positions of power and privilege can shape their experiences and to reflect on what this means for the creation of responsive, people centred health systems in Liberia.

6.5 Conceptual Underpinnings

This study draws significantly on the use of narrative and intersectional theory and combines these approaches to focus on exploration of individual illness experience, how this varies by individual's diverse social realities, and how the merging of these theoretical approaches can support the development of more responsive person-centred health systems. Within the subsequent section(s), we provide a foundational understanding of the two theories that we draw upon within the results and discussion section of the paper.

6.5.1 Illness Narrative Theory

When lives become disrupted by illness, narrated accounts of experience can support in understanding the meaning of illness within an individual's life context and in reconstructing the identity of the self(Thomas-MacLean, 2004, Whitehead, 2006). Illness narratives therefore present a useful approach in understanding the realities of living with NTDs from the perspective of affected individuals. Combined analysis across illness narratives from different individuals living with the same disease has proven useful in designing rehabilitation programmes and exploring coping mechanisms in the exploration of other chronic disabling conditions such as stroke (Pluta et al., 2015). Thus, exploration of illness experience, through narrative type which explore how sections of an individual's story are shaped by the narrator, and comparison between people living with the same or different NTD(s) may enable the development of a framework for understanding the subjective across a range of

disease conditions, contributing to improved understandings of how DMDI strategies could be integrated within people-centred health systems.

Exploring stories through 'narrative type' is not designed to simplify their complexities or see them as static, but instead supports a process of listening and understanding. Nor should stories be understood as matching one category within a typology alone; rather, the fluidity of stories causes them to move between narrative types at different times and in different contexts through a process of continuous evolution(Thomas-MacLean, 2004, Whitehead, 2006). In the following sub-sections, we reflect on different narrative types that were used to shape the analysis presented here (restitution, chaos and quest), first described by Frank (1995).

6.5.1.1 Restitution

Restitution narratives are the most common form of narrative; centred around a journey from health to sickness and a return to health, along a 'typical' health seeking journey predominantly focused around tests, diagnosis and treatments(Frank, 2013). The restitution plot is frequently constructed out of the desire of individuals to return to a 'pre-illness state' with the genesis of illness framed around a functional breakdown of the body that needs fixing, with less emphasis on causation(Whitehead, 2006). Individual hope for restitution, often presents as a desire to 'get well', rooted in a social and institutional construction of ill-health in Western allopathic medicine, in which occupation of the 'sick role'(Parsons, 1951) is a temporary state. The onus is frequently on the individual to find a way to return to the pre-illness state, reflecting modernist expectations that for every illness there is a 'cure', which can often result in loss of meaning of other parts of illness experience(Thomas-MacLean, 2004). For the chronically ill, or those who have occupied the sick role' for extended periods, stories of restitution can be inspiring, where individuals see a pathway in which they may return to their former selves, and scary, where no such pathway to recovery seems achievable(Whitehead, 2006). This is a particularly important consideration when considering illness, and the context of the restitution narrative under the umbrella of medical syncretism through which individuals concurrently hold multiple understandings of health and illness(Muela et al., 2002, Saleh et al., 2018).

6.5.1.2 Chaos

Chaos narratives reflect a loss of control, show no hope that life will improve and often involve detailed descriptions of suffering stemming from isolation, rejection and denial from medical professionals and wider society. Such stories can often be particularly difficult to hear, as individuals share vulnerabilities and despite repeated efforts to take control, perceive no viable way out of their current state – illness has become all consuming(Frank, 2013, Whitehead, 2006). These descriptions can become difficult to navigate with events becoming jumbled or broken; Frank (1995, p110) describes these as points of 'narrative wreckage'. Periods of chaos within narrative are critically important, and must be recognised to ensure that individual experience is not denied, and to provide appropriate care (Frank, 2013, Thomas-MacLean, 2004). Simplistically, chaos narratives depict people "sucked into the undertow of illness" whilst restitution narratives present illness as "transitory" (Frank, 1995p115).

6.5.1.3 Quest

Quest narratives show a level of acceptance of illness, with individuals providing reflection on what can be gained or considered useful from the illness process; that is, the individual is no longer trying to return to the 'pre-illness self'. Although no longer ill or for the chronically ill, illness has left a mark which shapes part of a new self or identity. Frank presents three types of quest narrative as follows: 1) Memoir narrative through which events are related simply; 2) manifesto narrative, in which illness becomes a motivator for social action or change; and 3) Automythology where illness is universally expanded to reveal fate or destiny. Critiques of the quest narrative as an ideal 'state' include the arguments that illness experience is rarely this clean cut and those who fail to 'rise' from the illness experience can become socially devalued(Couser, 1997).

6.5.2 Intersectionality Theory

Gender analysis within health research has been critiqued for failing to respond to developments in feminist theory that focus on complexities in social circumstances that can shape gender differences(Hankivsky, 2005, McCall, 2005). Popularised by

Crenshaw, and rooted in feminist ideologies and principles, intersectional theory responds to such critiques by considering gender in relation to other power asymmetries(Crenshaw, 1991). Intersectionality is an epistemological standpoint shaping research and activism (Larson et al., 2016) that seeks to:

> *"move beyond single or typically favoured categories of analysis (e.g. sex, gender, race and class) to consider simultaneous interactions between different aspects of social identity as well as the impact of systems and processes of oppression and domination" (Hankivsky et al., 2009p3).*

An intersectional approach is important to enable an understanding of the complexity of people's lives in considering how experiences and responses in relation to ill-health are shaped by social forces and inequalities (Bauer, 2014). Intersectional analysis requires consideration of the critical differences between social identity and social position. Identity formation should be considered as a developmental process that is relational, based on affiliation or interaction with broader social groupings and is informed by multi-level power relations(Bauer, 2014, Caiola et al., 2014). Processes of identity formation are fluid and can shift through space and time, although they are both shaped by, and shape, social position in specific contexts. Thus both identity formation and social position can inform health outcomes(Bauer, 2014). By resisting universalism, intersectionality enables consideration of how connected processes of identity formation and social position shape broader social constructs such as 'manhood', 'womanhood', 'motherhood', and 'patienthood,' and allows critical reflection on the broader social and historical context that informs their constitution(Caiola et al., 2014).

Quest, restitution and chaos narratives provide opportunity to explore links between context and individual experience of illness(Thomas-MacLean, 2004). Intersectional analysis of narrative exploration provides further depth by relating individuals' unique positions of power and privilege to narrative type. In combination they offer an approach to creating in-depth understandings of the subjective experience of chronic illness due to NTDs in specific social contexts, which can also contribute to

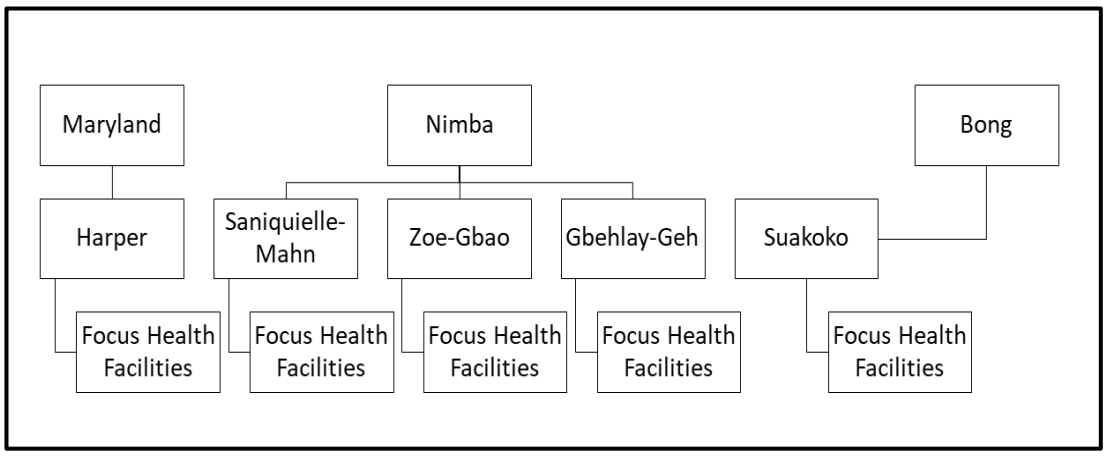
the generation of people-centred health systems approaches to promote supportive care (Thomas-MacLean, 2004).

6.6 Methods

6.6.1 Study Setting

This study took place across three counties in Liberia: Maryland, Nimba and Bong. These were purposively selected because they are: 1) known to be endemic for all the diseases of interest; 2) currently pilot counties for the supported role out of Liberia's integrated case management strategy; and 3) represent both geographical and socio-cultural diversity. Within each study county, study districts were purposively selected in collaboration with the Ministry of Health NTD Programme and County Health Team to assist in ensuring the relevance of study findings to programmatic activities. To select study districts, data on NTD-associated disease morbidity, recorded during the most recent round of mass drug administration, were utilized to identify areas with a high number of people affected by the NTDs of interest. Maximum variation across all study districts was also aimed for in geography (rural/peri-urban location/border/non-border) and socio-cultural context (ethnicity and language). One study district was chosen from Maryland and Bong counties and three from Nimba county. In each selected district, one health facility was selected based on the same sampling criteria as study districts. See Figure 10 for the study site sampling cascade.

Figure 10: Study Sites



6.6.2 Rational for Specific Disease Focus

Liberia's integrated case management plan focuses on: Leprosy, BU, Yaws, and clinical manifestations of LF, including lymphoedema and hydrocele. Leprosy, BU, onchocerciasis and clinical manifestations of LF are the focus of this study. Yaws has been excluded because: when this study commenced cases of Yaws were not yet identified in Liberia; Yaws manifests predominantly in children with whom it would have been difficult to engage using these methods; and there is growing evidence to suggest Yaws should be treated using mass drug administration therapies suggesting its alignment to prevention and control strategies rather than long term clinical and social management(Mitjà et al., 2015). Onchocerciasis is currently excluded from the integrated case management plan, based on rapid reduction in incidence of the disease. However, onchocerciasis is included within this study because there are still large numbers of individuals living with lifelong morbidity due to the disease, particularly in highly endemic countries such as Liberia, who require support.

6.6.3 Participant Recruitment

This study purposively sampled 27 individuals across three study counties who were affected by clinical manifestations associated with one of the diseases of interest in this study, to take part in illness narrative interviews (see Table 6). For a more detailed breakdown of cases, please see Table 4 (section 4.7.4).

Table 6: Summary of Case Studies Completed

	Age[1]	Lymphatic Filariasis	BU	Onchocerciasis	Leprosy	Total	
Men	**18-24**				2	**2**	**14**
	25-49	2	2	1	2	**7**	
	Over 49	1		2	2	**5**	
Women	**18-24**		2			**2**	**13**
	25-49	3	2[2]	1	1	**7**	
	Over 49			1	3	**4**	
Total		**6**	**6**	**5**	**10**	**27**	

[1]Age was used here as a representation of generation or social age. Many persons' in Liberia are not aware of their actual age and documentation of this is lacking. [2] One case study within this category was also a previous leprosy patient. The participant was selected on the basis that they had recently completed treatment for BU and therefore is counted in the summary table 6 in this category.

To ensure diversity in participant selection and recruitment, at selected facilities a sampling frame of all participants living with clinical manifestations of the diseases of interest was first developed based on cases recorded within Community Drug Distributor (CDD) registers. From this, participants were purposively selected to ensure maximum variation(Sandelowski, 1995) in age, gender and clinical manifestation. Once identified, we were introduced to potential participants in their homes, and given the opportunity to explain the research study, following which they were given the opportunity to ask questions and left with an information sheet (where literate). If they were willing to participate we arranged a convenient time to return to conduct the first narrative interview. Prior to beginning the interview, participants were again given the opportunity to ask any questions following re-explanation of the study and informed consent was then taken.

Two sampling strategies were used to identify people living with onchocerciasis since they were not recorded on CDD registers. First, we drew on the tacit knowledge of programme implementers who knew the locations of affected persons who were then sampled opportunistically. Second, we reviewed referral hospital skin snip registers to generate a sample frame of people who had tested positive for onchocerciasis, from whom we sampled purposively as described above.

Finally, we also utilised clinic records from a government health facility supported by a faith-based organisation and German Leprosy and Relief Association to recruit leprosy and BU patients from the surrounding communities. This allowed for consideration of variation in experience based on treatment type, and duration of disease/illness experience.

All interviews and follow-up interviews were completed at a location of the participant's choice. Participants were provided with a bar of soap following completion of both interviews as a token of appreciation. Soap was chosen due to its medicinal benefit for persons living with lymphoedema and was also valued by other participants. We chose to not give more than this, as we did not want participants to feel coerced into engaging with the study and based on guidance from the Liberian members of the study team this was seen as an appropriate and useful recognition for participation.

6.6.4 Illness Narrative Interviews

One local researcher (GN) conducted all narrative interviews with support and mentorship from LD who was also present during narrative generation. LD took notes of responses and non-verbal reactions, whilst GN facilitated the interview process in Liberian English or the appropriate local dialect dependent on county of data collection. Where GN was unable to speak the necessary local dialect, concurrent translation was provided by a community health worker in the study area who had been briefed in interviewing technique and the study purpose. We engaged with the same community health worker for all visits to specific communities.

Illness narratives often take a highly unstructured approach to allow for a greater detail of subjective reflection and ask an individual very broad-based question, such

as; can you tell me about your illness; and how has your life changed because of your illness?(Pluta et al., 2015). To generate each illness narrative, two interviews were completed with each study participant. During the initial interview with participants, a similar highly unstructured approach to generating illness narrative was taken; however a few modifications were made to allow for gentle guidance of the research participants toward themes(Thomas et al., 2009). A topic guide was developed, which rather than detailing specific questions, was structured around points or topics that could be addressed using a broad open-ended style of questioning. The guide or framework for the initial interview first sought to understand participants' social background, before focusing in on the illness experience linked to NTDs.

Following completion of the first interview, we listened to the audio recording and identified specific areas of the participant's story to explore in more detail. We also identified specific themes that were unexplored in the initial dialogue but critical in shaping the broader illness experience e.g. health seeking pathways. From this a list of key areas or questions to be explored in a follow up interview with participants was identified.

6.6.5 Analysis

The primary focus throughout analysis was to privilege the voice of the person who is 'ill'. Analysis drew on the use of traditional analytical methods including thematic analysis, which requires the '*slicing and dicing'* of data, as well as analytical steps that allowed for the holistic consideration of stories through narrative analysis that explored structure and content and was grounded by feminist intersectional theory(Thomas, 2010, Thomas-MacLean, 2004).

Riessman (1993) describes critical components in narrative analysis that allow movement between social context and experiences, identifying: 1) attending; 2) telling; 3) transcribing; 4) analysing; and 5) reading(Riessman, 1993). Attending means reflecting on the context in which narrative takes place. Throughout this study we have drawn on intersectional theory to examine the broader temporal and social context of the narrative, particularly how they are shaped by intersecting inequities. Telling was in the hands of participants as they decided what to share and how to

share information within their narrative journey. Transcription, analysis and reading was ongoing throughout the data collection period and following collection of the whole data set. Learning from one case study was frequently applied in asking questions of other participants. Following compilation of the narrative set, all interviews were transcribed verbatim, read and summarised and considered in relation to the social context. From these summaries a very broad coding framework was developed to explore links and patterns across narratives that could support health systems responses (Pluta et al., 2015) and applied to the data using NVIVO 11 software. Charts were developed and summarised to reflect variation in participant gender, generation and disease of interest and create analytical accounts by theme. Riessman, describes the process of analysis such as this as the generation of the 'metastory' whereby researchers synthesise what is included with the story and looks for ways to make comparisons across stories(Riessman, 1993). Within the analysis presented here, Frank's narrative types are drawn upon to analyse the illness experiences of persons affected by NTDs in Liberia. As Frank suggests, across all illness narratives, stories oscillated between various types which emphasised the complexity of experience. The illness journey was also shaped by intersecting inequities such as gender, generation, and geography.

6.6.6 Ethics

Ethical approval was granted from the Liverpool School of Tropical Medicine (16-070) and by the University of Liberia, Pacific Institute for Research and Evaluation Institutional Review Board (17-02-024). Informed consent was obtained for all participants, and consent processes adapted to meet individual communication needs e.g. where participants were illiterate (which was relatively common due to low levels of literacy across Liberia). Information sheets and consent forms were read aloud and explained to participants who were blind or visually impaired. All participants were adults.

We faced several ethical dilemmas in completing this study and took multiple steps to support the wellbeing of study participants and interviewers. For example, some of the participants needed medical treatment. One participant had been diagnosed with BU but despite countless attempts to access medicines, health systems delays

had meant that she had not yet begun treatment. Given the progressive and disabling nature of BU, this was a key ethical dilemma within the study. Following the interview, we decided it was our responsibility to do all we could to get the treatment necessary for this participant. Based on a strong, collaborative relationship with the national NTD team, we were able to source necessary treatment. Depth of detail within narrative accounts frequently revealed that participants were unaware of the diagnosis or degree of permanency of their condition and significant mental health challenges such as depression and suicidal ideation were often described. The ethical responsibility and dilemmas for researchers presented by such descriptions times felt insurmountable due to the highly constrained resources available for patients. We felt an ethical responsibility both to the study participants, and to interviewers in ensuring appropriate support for all involved. For participants, where we felt their descriptions of severe depression, anxiety or suicide were ongoing rather than historic, we discussed the option of possible support with participants. Where support was requested we indicated their vulnerability to the NTD team and/or the relevant members of the county health team. Following narrative interviews, the interview team made sure that we talked to each other about how such interactions had made us feel and sought advice and guidance for each other on the management of these situations. Despite these processes, the relative weakness of health system support services for mental health in study locations cannot go unrecognised. We see it as an ethical imperative to share the study findings around mental health in order to try to strengthen support services in this area. We have begun to do this through sharing of findings with: The Carter Center in Liberia (the key mental health implementation support partner); the National Ministry of Health Mental Health and NTD teams; and in an application for future funding to begin to develop support interventions in this area in collaboration with the Ministry of Health in Liberia.

6.7 Results

We have explored illness experience across a range of chronic conditions, enabling us to consider similarities and differences between findings for different diseases, as well as describing implications for health systems. Using everyday life as an entry point to narrative analysis allowed us to think critically and inductively about the

influence of social categories on experience. This has provided a space for the needs and values of people living with a range of NTDs to be articulated, contributing to the generation of a larger 'meta-narrative' that will likely have more weight in NTD policy design and programme planning and the development of more people-centred health systems(Fadlallah et al., 2019). Production of a meta-narrative was guided using Frank's narrative types as an analytical framework. Our results section is structured around these narrative types and sub-themes presented within each narrative type. We find the consideration of disease experience in relation to these narrative types particularly important when considering how to support people affected by NTDs throughout all 'phases or periods' of illness experience which is further explored in the discussion.

6.7.1 Restitution

Stories of restitution appeared to be the most common with many participants wanting to return to life circumstance before the onset of illness. Restitution was most dominant during two key periods 1) at disease onset or initial health seeking; 2) in pursuing a diagnosis and treatment seeking.

6.7.1.1 Health Seeking Triggers: Disease Onset and Illness Genesis

Perceptions of Severity

At the initial onset of symptoms, illness was frequently perceived as acute across all disease types, and mainly tolerated, as the impact on everyday life was minimal. It wasn't until acute symptoms such as blisters, rashes, swelling or increases in temperature were perceived as severe that participants considered themselves to be 'unwell', thus adopting the 'sick role'(Parsons, 1951). This usually related to a sudden inability to complete specific activities linked to existing identities as a mother, father, farmer or teacher. For leprosy and BU patients this tended to be when lesions or ulcers had reached a noticeable size and looked like more than a 'red mark on the skin'. For persons living with LF, particularly men, lymphoedema alone was not always a reason to seek healthcare. However, when hydrocele also developed or was experienced as the first symptom, this triggered health seeking.

> *'That's how it started; I said, "oh how I will tie lappa [African cloth used to tie babies to mother's back], then the lappa just loose like that and then the baby fell down?[the baby fell from her back]" then that's how it begins gradually…People begin to notice it, they say "but you are sick…your body [is] getting red, red spot[s] on it now". That's how it started'* ***(CS018, Female, Leprosy, Nimba).***

Pluralistic Belief and Treatment Systems

Restitution narratives have often been described in 'western settings' where biomedical understandings of disease and illness dominate. However, Frank argues that the restitution plot goes beyond hospitals and must also include different groups and contexts that shape the culture of illness. The restitution plot was framed with regard to syncretic beliefs and multiple providers by all participants. Illness genesis was frequently attributed to 'witchcraft' or 'African signs' and thus, the first point of call was frequently traditional healers known as 'country doctors'. More 'formal' health services were only sought when these options failed, either through choice or sometimes based on referral or recommendation by the 'country doctor'.

> *'Some people say that [it was a] witch and I myself…believe it that was witch. [But] when we came here (the hospital) the people tell us…that [is] not [a] witch oh, that [it is a] certain disease coming - that [is] just how it can treat the people. They started encouraging me then I myself started feeling fine. They said we will treat you then you will go [back] to school'* ***(CS013, Female, BU, Nimba).***

For some participants there was no clear dichotomy between seeking traditional or modern health services. Rather, both were necessary to deal with different parts of the illness experience. The 'modern' system was important to manage the 'biomedical' element of disease, whereas the country doctor was needed to manage the 'spiritual or 'causative' component of illness experience. However, both were necessary for return to a state of 'normality' and therefore pluralistic health seeking became essential to restitution. For others, particularly women and younger participants, 'modern medicine' in isolation was preferred, as it was seen to be more

effective. This was sometimes based on a distrust in county doctors, rather than a disbelief in 'country medicine'.

> *'I did that in the beginning because the kwee (modern) medicine is more effective than the country medicine [herb]'* ***(CS011, Female, Leprosy, Nimba).***

> *'I don't like country doctor because [they are] always creating problem[s] in your family. They will sometimes tell you that your mother, sister or grandmother is the cause of your illness'* ***(CS017, Female, BU, Nimba).***

In the immediate past, conflict in Liberia meant that at some points the traditional health system was the only healthcare available to many. In this context a reliance on and trust in these providers by many participants to ensure return to the pre-sick role is somewhat unsurprising, particularly for older generations.

Power and the 'Therapy Management Group'

Power was important in shaping health seeking decisions. Most participants described what has been termed a 'therapy management group'(Saleh et al., 2018), made up of key individuals within the household or community from whom they sought advice before seeking health care. The power relations between individuals in these groups and those who were seeking treatment often shaped their influence in decision making. For example, for younger people (those in their teenage years or early adulthood), care seeking decisions were frequently made by parents or caregivers; this often meant a reliance on country medicine, even where this was not the younger person's preference.

> *'When your parent[s] say [something] you will not tell them no. Because when you say no they will say 'the boy [is] rude - he [doesn't'] respect his parents'. So, you just have to go by their word, anything they say you will go there'* ***(CS019, Male, Leprosy, Nimba).***

For some women, decisions were made by their spouses, and they gained more autonomy only when their husband died or was not available. Health care providers

frequently became part of the therapy management group and their power as a vested authority was evident; many participants described taking medicines that they weren't clear about, but they placed trust in the clinician or country doctor.

6.7.1.2 Restitution Part Two: Diagnosis and Treatment Seeking

At the point of initial health seeking, participants frequently believed that diseases were curable and acute, but narratives started to move away from restitution when participants were unable to obtain the care or answers they wanted. Participants frequently described repeated episodes of health seeking to receive a diagnosis, oscillating between 'formal' and 'traditional' health practitioners, and between restitution and chaos narratives. Reasons for repeated episodes were threefold: 1) no answers were provided during initial health seeking visit; 2) participants felt their initial diagnosis was incorrect or inaccurate; 3) participants were seeking a possible cure, despite being told one may not be available.

For participants who had made multiple visits to the health system without receiving diagnosis or treatment, those who had been mis-diagnosed, and some who spent long periods of time receiving traditional treatment prior to entering the formal health system, delays in health seeking had sometimes led to permanent morbidity or physical disability with life changing consequences. Exacerbated morbidity challenged participants perceived ability of restitution to a life prior to the 'sick role' based on the often-collective experience of disease and illness within households and communities coupled with life altering impacts on the body. Despite this possibility however, the restitution narrative and 'cure' seeking remained strong within most illness accounts.

On receiving a diagnosis, participants narrated differing levels of acceptance. For some, diagnosis was a relief following years of health seeking, whereas for others, diagnosis was challenging to accept. Processing or accepting diagnosis appeared to be linked to the way in which the diagnosis was delivered, as well as the potential treatment or reversibility of condition. For instance, a few participants who had been told that lymphoedema was irreversible or that there was 'no cure' linked this understanding of the permanency of their condition to deterioration in their mental

health. In some cases, this shaped narrative direction toward a period of chaos whereas for others this strengthened the restitution plot by instigating additional health seeking, sometimes across borders where this was geographically and financially possible. Conversely, at this point, for many persons affected by Leprosy and BU, diagnosis coupled with availability of necessary medicines provided a positive prognosis for symptom alleviation, which presented a point of narrative 'where a sense of coherence could be restored' (Frank 2013 p61).

> *'I [was] still young I just want[ed] to get help. [I thought] even if I don't get the help I should get medicine that can even cool the sickness down…I couldn't leave from here to go to Ivory Coast and do business and come back'* ***(CS008, Male, Lymphoedema, Maryland).***

> *'when [the] doctor diagnosed me of having this leprosy, they told me "mama, you're welcome. You're here [in the hospital] for long time. The same way you're [a] human being, we that [are] here, we're human being[s]. If you want anything, you must let us know. Anything that you want eat, you must tell us. We [are] human being[s], you're [a] human being we are one [we are all the same, no discrimination]"'* ***(CS011, Female, Leprosy, Nimba).***

> *'I feel fine, I feel fine, I start praising him, that he is able. I feel fine and I tell him thank you because…I [have] been turning around with this problem for so many years…'* ***(CS022, Female, Leprosy, Nimba).***

6.7.2 Chaos

Narratives surrounding particularly traumatic or negative points of illness experience were often shaped by broader social factors such as being unwell during conflict periods and the impact on family life and community interactions. During descriptions of these events, narrative often became confusing and participants frequently jumped between sharing stories or experiences and present-day events or unrelated issues. This was particularly true for those still in the early stages of illness or within active periods of health seeking, whereas those who had been unwell

for longer, were able to provide a more coherent story and interpretation of events, normally structured around the use of dates or, for some older participants, around periods of conflict and calm.

6.7.2.1 Challenges to Identities and Psycho-Social Well-Being

Chaos narratives that triggered emotional responses to illness were often linked to disruption to a 'normal' health seeking journey, ambiguity around illness causation (including beliefs that sickness was due to witchcraft) and high levels of pain. Feelings of helplessness and/or worry were similar across diseases and often shaped by participant gender and generation as well as their pre-illness identity as a 'school-child' 'parent' or 'household provider'. For example, for younger participants, being unable to go to school or interact socially with their peers created a huge sense of loss; however, for older participants who had got sick later in life, worry was linked less explicitly to current illness experience and more focused on ageing and the reality of no longer being able to do the things they used to do. For participants who constructed their identity prior to illness around being a parent or household provider, transition to the role of a 'dependent' and limitations to their ability to provide for their family contributed toward a chaos narrative that often articulated a general sense of worry or anxiety about how to fulfil the needs of their families and households. Some male participants also experienced a challenge to their gendered identity or masculinity, as they saw it as their role to be able to support their family's needs but now faced challenges in providing food as they were unable to farm, work hard or travel far from communities.

> *'Even my children who I supposed to help them…[there is] no other means for me to help them [which] also [causes] a bad feeling...'**(CS012, Male, Leprosy, Nimba)***

Extreme experiences of social isolation coupled with feelings of helplessness, worry and anxiety often resulted in suicidal thoughts and description of suicidal attempts. These were either related to their own direct experiences or '*others like them'* within their community. For some participants, particularly those currently receiving treatment or those who were unclear about their future disease outcome, these

thoughts were still present. For others the description of these thoughts and events was historic and something which they had worked through, usually through religious faith or based on a renewed sense of purpose or belonging within the community. Thus, religious belief frequently supported participants in redirecting narrative trajectories toward quest or restitution.

6.7.2.2 Stigma and Temporality of Disease

Chaos and restitution narratives frequently co-existed, and mental ill-health often remained despite biomedical treatment of disease. Participants frequently described that although they had been told they were 'free' from disease, their physical condition, perception of 'self' and mental wellbeing did not return to a pre-illness state, compromising their sense of restitution. Particularly for persons affected by BU, even in the absence of physical morbidity, the social isolation and stigma associated with the illness experience had long lasting impacts on mental-ill health, with one participant narrating that *'my friends not coming around me anymore still made me want to kill myself'*.

In addition, persons who had been treated for leprosy, whether treated externally or within their community, also described incidences of abuse or/and enacted stigma that resulted in further isolation, despite their best attempts, with support from the health system, to re-integrate into community activities. For many, this was presented chaotically within their narrative. However, participants who had had additional time to reflect on such events frequently used specific dates and had counted the time elapsed since their occurrence, emphasising the significance of the experience in their narrative and its impact on their life trajectory. Enacted stigma and abuse for these individuals was difficult to challenge, and even where community leader support was given this did not change the outcome for patients. Otis's, story encapsulates such experiences:

> *'Otis was issued with a piece of paper that certified him free of leprosy on finishing in-patient treatment. The town chief communicated this to the community. However, he was accused of witchcraft and was beaten by his relatives because of the remaining*

physical manifestations of disease such as sores and loss of digits. The beating caused impotence and his wife subsequently left him. Otis also described more traditional approaches to re-integration, including 'taking an oath' [drinking a specific drink and eating a specific meal determined by the country doctor]. He felt that this improved his inclusion, but from observation he showed signs of social isolation and relied on alcohol. He still lived alone and said that no-one would eat with him. ***(CS010, Male, Leprosy, Nimba)***

Ongoing oscillation between periods of chaos and restitution were particularly noticeable amongst persons affected by lymphoedema, leprosy and BU. Acute attacks or 'flare ups' for lymphoedema patients or ongoing pain often led to repeat health seeking visits for affected persons. Debilitating attacks or periods of intense pain were often scary for everyone involved and induced a return to chaos. For many participants living with LF, not knowing their diagnosis or the irreversibility of their condition, presented an ongoing sense of hope for a 'cure'. However, many expressed that if this 'condition' was permanent then they would not want to go on living. Diagnostic communication is thus crucially important.

'When I know that [the pain] is serious…then I can go to [the health centre]…Like, last night I was not feeling too fine in my body, I went there this morning, they gave me some pain tablets to take...Because now, I [am] not on leprosy tablet[anymore], I [am] on reaction medicine and…yesterday they said that I must rest from the medicine. And when I [did] not take it yesterday, last night my body hurt me [so] now, I told them. They say they want to observe…how my body will be looking this week' ***(CS021, Male, Leprosy, Nimba).***

6.7.3 Quest

Many of the narratives demonstrated an overall sense of quest narrative as they were essentially memoirs of individuals reflecting on their illness experience, where, through this research researchers and participants came together to co-create illness

stories. Many individuals, predominantly those seeking a diagnosis or cure for their illness, were still in periods of chaos and restitution. For some a tension remained between narrative type because of mental ill-health, social isolation and stigmatisation. However, through their descriptions many participants showed strong elements of memoir narrative; through the process of telling they had created a meaning out of their illness. No participants expressed an active choice in processing their new identity or sense of self, and thus manifesto narratives were lacking as well as minimal demand for social change.

6.7.3.1 Internalisation of Condition and Adapted Lives

During periods where participants perceived their illness to be at its worst, they hid themselves away from friends and in some cases family. This was normally based in fear of embarrassment or experience of enacted stigma, that frequently led to internalisation of broader social norms or beliefs and self-stigmatisation. During these periods' participants described taking actions such as separating themselves during meal times and using separate cooking and eating equipment; this was particularly common amongst leprosy and BU patients. One older leprosy patient described '*eating alone, not using other utensils in the house that other family members used…I don't want [them] to get this sickness that I have'* ***(CS011, Female, Leprosy, Ganta)***. Despite this, '*my people, the ones who were here, my sisters, [would say] don't make yourself look too sorryful (pitiful). Eat with us and bath in our bathing buckets…'****(CS011, Female, Leprosy, Ganta),*** however she still continued to isolate herself. Women living with onchocerciasis often described isolating themselves from the community by staying indoors or close to the house, due to fear of what would happen to them if they moved outside. Janet was living with onchocerciasis and dependent on her mother due to such fears. Her mother had set up a rope for her to follow to be able to defecate close to the house, but Janet described being fearful of attack if she moved much further than this.

> *'I am used to it, I am used to blindness. [I could] be walking around-*
> *I even know the road, but it scares me, it is dangerous to me*

because I am not seeing what is ahead of me so that['s] what cut it (her movement) short' ***(CS014, Female, Onchocerciasis, Nimba)****.*

These accounts of self-stigmatisation and social isolation presented an acceptance of condition and/or social circumstance that recognised a life change and associated elements of a quest narrative. In contrast to 'positive' quest narratives frequently described in the literature, these individuals had adapted their lifestyle in ways that they felt were protective for their safety and wellbeing and 'this became their life now'. These accounts are as important as positive accounts of illness in understanding individual realties.

6.7.3.2 Coping Strategies: Alternate Identities, Transient Living and The Role of Faith

Age was a critical factor in moving toward a memoir narrative. Many participants who had become sick later in life were relatively happy to assume a new identity as a 'dependent', normally linked to expectations of sickness was in the later stages of one's life course. Older people occupying the sick role for long periods of time evoked compassionate empathy and care from the wider community, in contrast to the negative responses experienced by younger individuals.

> *'I am weak in the body. I am not physically strong [anymore] to be looking for things for living (a livelihood). All I want is for someone to care for me. In the morning, they prepare me breakfast, lunch…dinner…that's all I want now…so nothing I have to worry about. I am not looking for money to build [a] house, I have lived my life. My husband [died] some years back'* ***(CS011, Female, Leprosy, Nimba).***

Religion and faith were critical in the way participants interpreted their illness experience and in looking to the future or navigating periods of trauma and chaos. Some participants, particularly those living with leprosy and onchocerciasis, frequently described their faith and the support they received from religious individuals or organisations as key in shaping positive transitions in their mental ill-health. The comfort they found in faith often provided a platform for forgiveness

toward other community members following experiences of extreme stigma and violence they had experienced associated with their illness and provided a space of hope that reduced a desire to 'no longer go on living'. Participants also used faith to accept and rationalise their experience, i.e. 'it was part of God's plan.

> *'What came to my mind first…I wanted to commit suicide…but God came into other people['s] heart and came into my heart…so I looked up to God and take treatment I will get well. It [has] been long - it took two years - for a young man to sit for two years it's hard …and I have family too. Comfort…only comfort besides that I'm not feeling nothing else. What I use[d] to do I can't do it no longer and then only God kept me living'* ***(CS025, Male, Buruli Ulcer, Bong)***.

Some leprosy participants describe leaving their place of residence to seek safety and escape stigma and discrimination. Safe spaces were frequently obtained by returning to places where they had previously felt safe and secure, normally the communities close to the place where they had previously received Leprosy treatment.

> *'At times when I am feeling bad…I will leave this community and go to another community to be there for some time'* ***(CS009, Male, Leprosy, Nimba).***

6.7.3.3 Collective Support and Shared Experience

Participants who were living in previous leprosy colonies or communities in and around rehabilitation facilities did however describe a change in the context and sense of community over time. They described how the conflict, inward migration to communities and recent changes in the country's economy had led to people being less supportive of each other or willing to interact to improve individual circumstance. This highlights the temporality of spaces and places in shaping illness experience and key points of transition in patient narratives.

Where safe spaces were not available to participants, there were often key individuals within communities from whom they sought support. For example, one

person affected by leprosy described frequently seeking advice and guidance from the officer in charge of the facility on how to handle community relationships.

Most participants expressed a lack of awareness of others around them who were sharing the same illness experience or faced challenges in interacting with them based on personal mobility, distance, or differences in age, gender and/or social position. However, in circumstances where groups of 'patients' were able to interact this was positively received and supported them in processing the illness experience, including shaping the treatment seeking journey, processing of diagnosis, and sharing experiences and understandings. In addition, participants who were currently being or had been treated for leprosy within an in-patient facility particularly described the sense of solidarity amongst affected persons that ongoing patient interaction had facilitated.

> *'when I was there, I was taking treatment. All of us were also leprosy patients. We used to joke one another, I not feel bad because we all joked one another… we joke every day'* ***(CS010, Male, Leprosy, Nimba)***.

6.8 Discussion

6.8.1 NTDs, Feminist Intersectional Theory and Narrative Discourse

To our knowledge, this is one of the first studies to use a narrative approach, most specifically Frank's narratives types (restitution, chaos and quest) to interrogate experience of chronic disabling conditions within LMICs and is the only study to apply such an analysis to NTDs. Despite their proven utility in feminist and intersectional research(Christensen and Jensen, 2012), narrative methods have not frequently been used to elicit the views and experiences of people affected by NTD related morbidity. Our use of narrative has allowed for consideration of how illness experience and identity formation is shaped by ongoing and changing relationships to social structures that are influenced by multiple historical oppressions (e.g. conflict and colonialism) from the vantage point of the most marginalised. Social realities and the construction of knowledge, has, as far as possible, been guided by participants themselves(Bowleg, 2012, Caiola et al., 2014, Prins, 2006). This is not to

argue that narrative and it's use within this study offers some form of 'hyperauthentic' truth; rather it provides an opportunity to consider content within the narrative as well as how diverse social categories interact to give narrative meaning(Christensen and Jensen, 2012). The narratives presented here are deeply grounded within the unique political and historical trajectory of Liberia (a nexus of conflict, colonialism and aid-dependency) and the findings reflect the experiences of many individuals who are already known to the health system. Although the empirical generalisability of these findings is likely tempered by these facts, the broader conceptual implications and health systems strengthening recommendations have a wider resonance. Although some meaning in our narrative analysis may have been lost in translation, we have conducted co-analysis between researchers from the UK and Liberia and sought clarity in our interpretations from affected persons.

6.8.2 Situating NTDs alongside other chronic conditions

In common with many chronic conditions, such as breast cancer, stroke and HIV, predominantly in high income settings, restitution, chaos and quest narratives all surfaced in the experiences of those living with life altering morbidity and disability resultant from NTDs affecting the skin(Whitehead, 2006). Across all narratives, chronic illness or morbidity associated with NTDs represented a key moment of 'biographical disruption' or 'narrative wreckage' for most of our participants(Bury, 1982, Frank, 2013) which triggered the commencement of the restitution plot(Frank, 2013). Complex health seeking pathways, aetiologies and medical syncretism frequently meant that adoption of the 'sick role' was initially acceptable, but when the reality of permanency of condition was identified, this became a critical challenge for many people, triggering a transition to periods of chaos and significant psycho-social difficulty. This is consistent with findings of studies on HIV and breast cancer(Ezzy, 2000, Thomas-MacLean, 2004). However, in such studies, positive prognosis is often a key trigger of return to the restitution plot. Positive prognosis was not possible for many individuals within this study because of exacerbated morbidity due to delays in obtaining effective treatment. In some cases, diagnosis can provide a moment of solace by putting an end to constant health seeking and

presents a way forward for participants that restores progression within their health seeking journey. This echoes the experiences of people affected by chronic fatigue syndrome/myalgic encephalomyelitis in the UK (Whitehead, 2006) and was particularly evident amongst leprosy and BU patients within this study. Thus, early case detection that limits loss of hope of positive prognosis, coupled with effective diagnostic communication are of critical importance to patient well-being, irrespective of chronic condition. Whilst early case detection and clear and accurate diagnosis will not necessarily reduce periods of chaos for affected individuals they should aim to contribute toward enabling the health system to better support individuals through these periods.

In common with most findings from narrative studies, the illness experience of our participants brings with it a change in identity(Whitehead, 2006). However, supporting participants to accept and embrace a new identity is a key, ongoing challenge for the Liberian health system. An intersectional lens is essential to emphasise how biographical disruption(Bury, 1982) within narrative accounts varies between individuals and therefore how to support affected individuals in navigating their illness experience. We identified that the extent to which illness is disruptive is negotiated and mediated within different spaces and places intersecting with different social stratifiers. For example, generation was a critical component of individual identity that shaped the impact of disease; that is older people often found 'sickness' more permissible, and frequently experienced less enacted stigma. Conversely, a strong reliance on traditional health systems had the potential to exacerbate physical impacts of morbidity. For younger generations, illness was perceived as life altering, presented severe challenges for individual psycho-social wellbeing and impacted individual gendered identities within the household. Power relations within the household and community also frequently impacted the care seeking journey as mediated through the therapy management group.

6.8.3 What does this mean for health systems strengthening and people-centred responses to NTDs?

Each of these factors needs to be considered in the specific context of Liberia, where the health system is: relatively fragile having undergone prolonged periods of shock related to conflict and EVD; biomedically orientated and hugely reliant on donor-driven, 'vertical' approaches that concentrate on disease surveillance and outbreak prevention; and urban centric in terms of services and staff expertise due to poor rural infrastructure(Bell et al., 2017, Kruk et al., 2010, Thomas et al., 2017). However, the broader lessons for understanding realities of those living with chronic disabilities and implications for people centred and responsive health systems have resonance beyond Liberia.

6.8.3.1 Moving Beyond the Curative Model

Our findings suggest that the design of health systems around curative disease models misses opportunities to support patients in relation to all elements of their illness experience, by reinforcing the notion that illness is a temporary state and neglecting to address the complex interplay of physical disability, mental ill-health and social stigma associated with NTDs(Tora et al., 2018). Thus, health systems need to adapt to create a continuum of care that offers opportunities to empower persons affected and extends beyond the medical management of disease. Frank would describe this as supporting affected people(Frank, 2010) to move toward a manifesto (quest) narrative, through which individuals make an active choice in processing their new identity and begin to demand social change to meet their needs. Approaches shown to facilitate these processes include the establishment of patient support groups for leprosy in India and Nepal(Cross and Choudhary, 2005, Deepak, 2003) and using patient advocates(Van Brakel and Lusli, 2017) to provide peer to peer patient support in Indonesia. Such group interactions have been shown to increase collective voice and strengthen social accountability processes, whereby individuals affected by chronic illness and disability feel more able to challenge existing social hierarchies and make demands of health systems(Hamill et al., 2019). Individuals become active

participants as well as beneficiaries in meeting their own care needs(Tora et al., 2018).

Similarities in illness experience across a wide range of NTD related morbidity identified within this study present an opportunity for the consideration of integrated support groups in Liberia. However, existing social hierarchies in relation to gender and generation need careful consideration in group composition. Geographical diversity in patient location may make the establishment of such groups challenging in some areas; however, given the similarity in experience across multiple NTDs resultant in chronic morbidity, similar experiences may also be true of other chronic conditions. Integrated responses across multiple chronic conditions may therefore be a viable alternative to NTD-specific support groups at the primary health care level in Liberia.

6.8.3.2 Responding to Psycho-Social Support Needs

Our findings, in common with other studies of a range of acute and chronic illness, show that illness lasts far beyond treatment cessation(Thomas-MacLean, 2004). This was particularly true of persons affected by leprosy and BU, who experienced significant periods of mental ill-health despite successful 'medical' treatment. Frank argues that chaos narratives should be a constant reminder to us to not accept quest narrative uncritically, i.e. even for individuals who have moved toward periods of quest, periods of chaos will still occur, illness, particularly chronic illness, is transitory(Frank, 2013). The strong and dominant accounts of suicidal thoughts and attempts, depression and anxiety within participants' narratives indicate that, as has been suggested in other NTD related studies(Litt et al., 2012), mainstreaming the provision of psycho-social support within NTD programmes is essential. Peer support can again be useful in this regard, but the health system can also take key steps to ensure individual needs are identified and responded to. Establishing integrated case management teams that engage mental health professionals to carry out psycho-social needs assessments at point of diagnosis could be a key first step in signposting individuals to the support services that they need. This will also rely on a strengthening of referral systems between curative or preventative services and those which provide more long-term chronic care and psycho-social support.

Challenges with this approach are however likely, as psycho-social support services provided through the government health system are still limited in Liberia and other contexts across sub-Saharan Africa, are often highly stigmatised, and themselves need strengthening. The NTD community, should therefore also learn from more community-based approaches to the provision of psycho-social support that seek to redress power imbalances within communities that can lead to social isolation and stigmatisation which negatively impact mental well-being; examples are the development of 'friendship benches'(Chibanda et al., 2015) or the 'Stepping Stones' community-based learning programme on HIV(Jewkes et al., 2008, Paine et al., 2002). We also identified that traditional healers or country doctors are clearly a well trusted pillar of the pluralistic health system in Liberia; considering how to build on the social capital of these individuals through their engagement in the provision psycho-social support could also be considered.

6.8.3.3 Addressing Diagnostic Delays

For affected individuals in our study, diagnostic delays often rendered participants in a position of '*biographical turmoil'*: they know they are sick, but they don't know why or the cause, thus the restitution plot gives way to chaos(Frank, 2013). Health systems, both formal and informal have a responsibility to meet the detection and diagnostic needs of populations as a gateway to effective treatment and thus systems strengthening in this area is essential(Mitjà et al., 2017). Training of community health workers has proven an effective case detection and referral strategy in relation to BU in Cameroon(Corley et al., 2016), and has been shown to have potential in Liberia, however, better utilisation of the extensive evidence on maximising the performance of CHWs(Kok et al., 2014, Raven et al., 2015) could strengthen the role of CHWs in the management of NTDs and is crucial to the effectiveness of intervention. Understanding how to engage and support 'country doctors' to identify and refer cases is also likely to be of huge benefit to promoting the early and accurate case detection of NTD patients within Liberia.

6.9 Concluding Thoughts

Illness narratives presented in this study are unfinished, as they describe lives and realities that are still ongoing(Whitehead, 2006). The Liberian health system and broader NTD community has an opportunity to respond to the needs and priorities of affected persons as they are presented here. The integrated case management plan in Liberia is essential and a step in the right direction toward responding to these needs, however resource and systems constraints currently limit its potential in maximising support for individuals and their communities. Narrative has been recognised as something which should be given greater weight in policy formation and decision making(Fadlallah et al., 2019). The emotive power of narrative can be utilised to influence the value base of policy makers, which is frequently the driving force behind any policy decision(Fadlallah et al., 2019). The 'meta-narrative' presented here or specific case studies from within this data could be utilised by programme implementers within Liberia to leverage resources and instigate health systems and policy reform that is guided by the needs and values of affected persons' and their communities. There is a current 'window of opportunity' for policy and programme reform in Liberia to ensure that integrated morbidity management programmes for NTDs respond holistically to the needs of the most marginalised, thus contributing to health systems strengthening for more equitable people-centred care.

6.9.1 Acknowledgements

We would like to thank all the participants who took the time to engage with us to be a part of this study and shared honest and challenging accounts of highly personal experiences. We would also like to extend our gratitude to the Government of Liberia, Ministry of Health, National NTD programme and the County Health Teams of Nimba, Bong and Maryland who facilitated district and community access and provided ongoing logistical support.

Chapter 7: Results- Key Informant Interviews, Narrative Case Studies

7.1 Chapter overview

This chapter draws together analysis from all methods drawn upon within this thesis to support in addressing objectives:

1. **To understand the Liberian health systems response to chronic disease and disability with a specific focus on onchocerciasis, Buruli ulcer, lymphoedema, hydrocele and leprosy.**

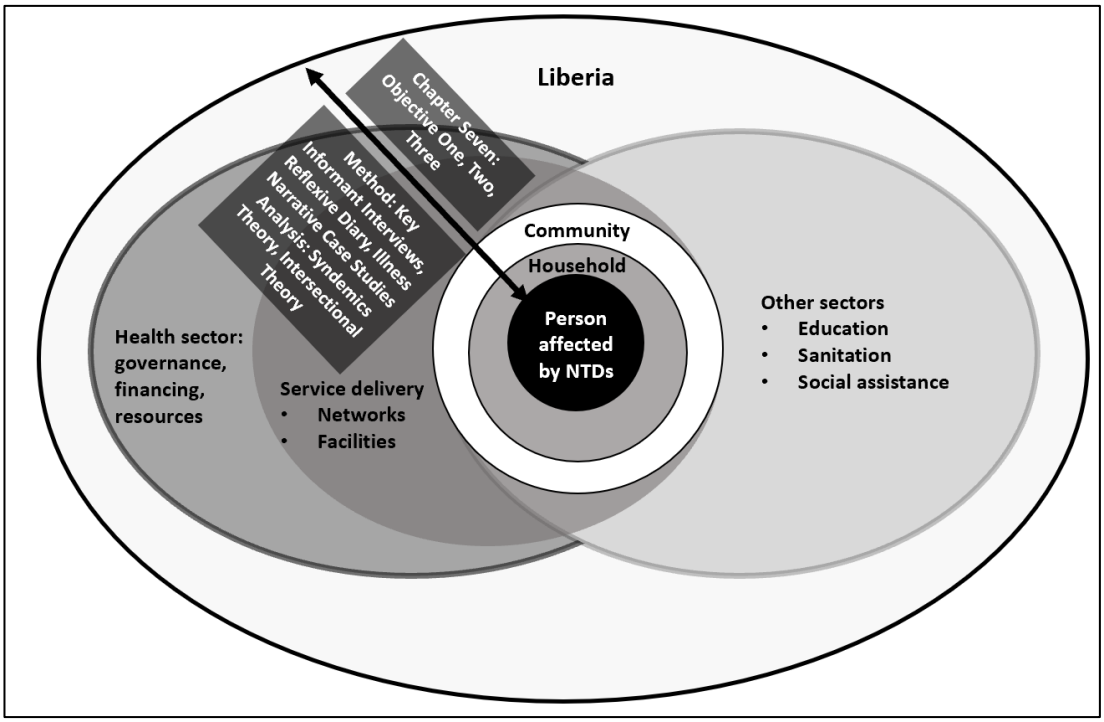
2. **To understand individual experience of living with one or more of selected NTDs from the perspective of affected individuals and members of their household with a focus on how this varies by differing axes of inequality such as age, disability and gender.**

3. **To elucidate what medical, social and economic strategies would allow for more equitable and effective support and management for selected NTDs from the perspective of affected individuals, with exploration of how such strategies could be integrated between diseases and within the wider health systems response to chronic disease and disability.**

Figure 11, shows the positioning of this chapter within the overall thesis structure. Specifically, it brings together perspectives and analysis from **key informant interviews, my reflexive diaries, and illness narrative case studies** to consider how the post conflict context in Liberia has created a risk environment that shapes negative health outcomes for people affected by NTDs. By advancing syndemic theory to include intersectional thought, it explores the biosocial relationship between NTDs and mental distress in the context of structural violence in Liberia. The chapter first introduces the importance of syndemic theory for understanding health inequity and highlights synergies between syndemic theory, intersectional thought, structural violence and people-centred health systems. The merged finding and discussion section is structured around a model of syndemic thinking that allows for consideration of: the social-psychological processes that shape how co-occurring

conditions interact; experiences of affected persons and their social networks and how this varies by factors that shape individual identities e.g. age and gender; and health and social system responses. The cumulative analysis presented advocates for the provision of 'syndemic care' in relation to NTDs and contributes toward suggestions of what medical, social and economic strategies would allow for the more equitable and effective management of NTDs in Liberia.

Figure 11*:* Positioning of Chapter 7 within Overall Study Framing



This paper is under review with *Social Science and Medicine.* As described in the manuscript title page, I led the analysis, conceptualisation and production of this paper which included the production of initial drafts, revisions, finalisation and submission. Other authors were either engaged in data collection (see section 4.5), and/or manuscript reviews in line with their role as supervisors or project partners. RT and ST had a greater role than other authors given their responsibility as PhD supervisors. As this paper draws multiple elements of this thesis together, there is some overlap in this chapter and chapter 8.

A syndemic born of war: Combining intersectionality and structural violence to explore the biosocial interactions of neglected tropical diseases, disability and mental distress in Liberia

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Keywords: Syndemic, Intersectionality, Structural Violence, LMICs, Health Systems, qualitative, Neglected Tropical Disease, Mental Distress

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Writing Review and Editing- LD, ST, RT, GN, KK, AB

7.2 Abstract

We apply syndemic theory to explain the biosocial relationship between NTDs and mental distress in the context of structural violence in Liberia. By advancing syndemic theory to include intersectional thought, it is apparent that structural violence becomes embodied in different ways through interacting multi-level (macro, meso and micro) processes. Through the use of in-depth qualitative methods, we explore the syndemic interaction of NTDs and mental distress from the vantage point of the most vulnerable and suggest that: 1) the post-conflict environment in Liberia predisposes people to the chronic effects of NTDs as well as other 'generalised stressors' as a consequence of ongoing structural violence; 2) people affected by NTDs are additionally exposed to stigma and discrimination that cause additional stressors and synergistically produce negative health outcomes in relation to NTDs and mental distress; and 3) the impact and experience of consequential syndemic suffering is shaped by intersecting axes of inequity such as gender and generation which are themselves created by unequal power distribution across multiple systems levels. Bringing together health systems discourse, which is focused on service integration and centred around disease control, with syndemic discourse that considers the biosocial context of disease interaction offers new approaches. We suggest that taking a syndemic-informed approach to care in the development of people-centred health systems is key to alleviating the burden of syndemic suffering associated with NTDs and mental distress currently experienced by vulnerable populations in resource-limited settings.

7.3 Introduction

Syndemics can be described as '*synergistically related' epidemics that cluster around harmful conditions' (Tsai, 2018).* Syndemics occur where social and structural inequalities create increased physical and behavioural vulnerabilities to ill-health(Engelman et al., 2016, Singer et al., 2017b). Neglected Tropical Diseases (NTDs) are a group of acute and chronic infections that frequently occur as a result of poverty, poor environmental conditions and social disadvantage(Hotez et al., 2016, Singer and Bulled, 2012). The intersections between NTDs, disability, and mental ill-health are increasingly recognised globally(Bailey et al., 2019, Litt et al., 2012). Chronic morbidity resultant from many NTDs, particularly those affecting the skin - including lymphatic filariasis (LF), leprosy, Buruli ulcer (BU) and onchocerciasis - is well known and largely documented from a medicalised perspective(Mieras et al., 2016, Bailey et al., 2019). Additionally, studies over the last five years have revealed significant co-morbidity between NTDs and depressive disorders (Bailey et al., 2019, Litt et al., 2012). Highlighting epidemiological associations between NTDs, disability, and mental disorders is critically important; however, it is now widely recognised that understanding the biosocial connections between diseases is essential in responding to disease interactions and their impact on the health and wellbeing of affected populations(Bailey et al., 2019, Ferlatte et al., 2018, Singer et al., 2017a, Singer et al., 2006). The current focus on physical and mental co-morbidities associated with NTDs is generally framed within a bio-medical perspective, with limited consideration of the bio-social context (Parker and Allen, 2011). Thus, an evidence gap remains in understanding the social and structural processes that shape disease interactions between NTDs, disability and mental ill-health and the most appropriate health systems responses.

Syndemic theory, offers a conceptual basis for exploring and making visible the bio-social aspects of disease(Mendenhall, 2014). Through blending multiple theories from the social and medical sciences, syndemic theory supports the development of understandings of disease experience beyond biological and epidemiological clustering to consider how social, political and economic forces shape the relationships between diseases and illness experiences to perpetuate health

disparities and poor social condition(Mendenhall et al., 2017, Singer et al., 2017a, Tsai, 2018). However, robust empirical analysis of syndemic relationships has been described as lacking (Tsai, 2018). In response, Tsai (2018) argues for the use of multiple complementary strategies to further advance syndemic theory; one such strategy is the incorporation of insights from anthropological fieldwork into the study of syndemic suffering (the lived experience of the syndemic clustering of disease)(Mendenhall et al., 2015). Through the use of an in-depth qualitative methodology, we have explored patterns and pathways through disease from the viewpoint of affected populations to develop explanations and understandings of how forms of power at the macro (national/political-economy), meso (institutions and social processes) and micro (individual and household) level interact to shape specific outcomes in relation to health and wellbeing (Ferlatte et al., 2018, Tsai, 2018). In-depth qualitative data can thus provide the individual and community level foundations that support the explanation of macro (national)-level observations established through epidemiological studies(Tsai, 2018).

Structural violence, as a critical underpinning of syndemic theory(Singer et al., 2017a, Tsai, 2018), encourages detailed consideration of how unequal global and local political-economies and social organisation inflict embodied harm on people (Farmer, 1996). These macro-level determinants do not, however, impact all individuals in the same way or operate in isolation, rather, they intersect with individual identities (which are themselves constituted by intersections between sex, age, economic status etc.) to shape nuanced and shifting experiences and outcomes for individuals within populations(Connell, 2012, Crenshaw, 1991, Simpson, 2009). In considering syndemic interactions(Singer et al., 2017a) between NTDs, disability and mental ill-health, it is therefore important to consider the operation and intersection of power relations at multiple levels, from the macro to micro. Structural violence, when used as an analytical framework in isolation, has been critiqued for failing to consider how interactions between varying forms of violence (physical, economic, political and social) interact and are mediated by characteristics at the micro or individual level to create specific and nuanced experiences of health and social inequalities (Shannon et al., 2017). Intersectional theory supports such

considerations as it enables exploration of how the multiple social locations of individuals intertwine to shape health inequities that result from a web of mutually reinforcing and intersecting power relations creating a 'specific matrix of domination'(Bowleg, 2012, Collins, 2002, Connell, 2012, Crenshaw, 1991, Ferlatte et al., 2018, Hankivsky, 2005, Hankivsky and Cormier, 2009, Hankivsky et al., 2009, Larson et al., 2016, Simpson, 2009). Intersectionality provides us with the opportunity for a cumulative exploration of individuals micro-positioning within both macro structural and social processes(Collins, 2002), supporting the understanding of the complexity of people's lived realities of relationships and responses to health and illness(Bauer, 2014). Thus, when applied together as analytical tools, intersectional theory and structural violence have the potential to advance the empirical study of syndemics, supporting explorations of how syndemic interactions are underpinned by mutually reinforcing systems of both structural and social oppression to perpetuate individual suffering in specific contexts (Collins, 2002, Ferlatte et al., 2018, Mendenhall, 2014, Mendenhall, 2016).

Liberia has a deeply complex political and social history as a result of a unique post-slavery, post- colonial experience. Deeply rooted disunity between 'settlers or colonists' (freed African American slaves who had declared Liberia an independent nation in 1847 from the American Colonisation society) and indigenous peoples are frequently cited as the roots of protracted unrest and fragility (Johnson-Sirleaf and Miles, 2009, Radelet, 2007). These fractures resulted in 25 years of gross economic mis-management (GDP fell by 90% in less than two decades) and a 14-year civil war (Johnson-Sirleaf and Miles, 2009, Kruk et al., 2011, Radelet, 2007). 2003 marked the end of two periods of conflict, both of which devastated the country's health and social infrastructure, contributing to widespread extreme poverty, an absent education system, and a lack of institutional capacities(James et al., 2019, Yaya et al., 2019, Kruk et al., 2011, Radelet, 2007). For many Liberians, this nexus of factors shapes poor health outcomes and has created a reliance on alternative forms of health care such as traditional medicine (Yaya et al., 2019). Most recently the Ebola outbreak triggered the almost entire collapse of the Liberian health system(Gausman et al., 2019).

In this paper, we use in-depth qualitative methodology to explore the case for a syndemic relationship between NTDs and mental distress in the context of structural violence in Liberia. We use the term mental distress to refer to descriptions of stress, anxiety, depression and suicidal thoughts within participant accounts. We argue that a key pathway through which NTDs and mental distress are linked is as a result of NTD-related chronic morbidity (e.g. lymphoedema) and disability (as a result of associated stigma and social exclusion). However, not all persons affected by NTDs experience chronic morbidity and or disability. We therefore use the term NTDs within this paper to encompass all forms of disease experience, including chronic morbidity and disability.

By drawing on Meyer (2003) 'minority stress model' Mendenhall et al. (2017) model of syndemic approaches to health, we suggest that: 1) the post-conflict environment in Liberia predisposes people to the chronic effects of NTDs as well as other 'generalised stressors' as a consequence of ongoing structural violence; 2) people affected by NTDs (as a minority status) are additionally exposed to both 'internal and external minority stressors' (largely driven by stigma and discrimination) that synergistically produce negative health outcomes in relation to NTDs and mental distress; and 3) the impact and experience of both generalised and minority stressors and consequently syndemic suffering is shaped by intersecting axes of inequity such as gender and generation which are themselves created by unequal power distribution across multiple systems levels. Finally, by drawing on narrative methods and intersectional analysis we explore the nuanced experiences and realities of syndemic suffering from the vantage point of affected populations, and consider how such approaches aid in supporting the design of multi-level person-centred responses to syndemics in LMICs.

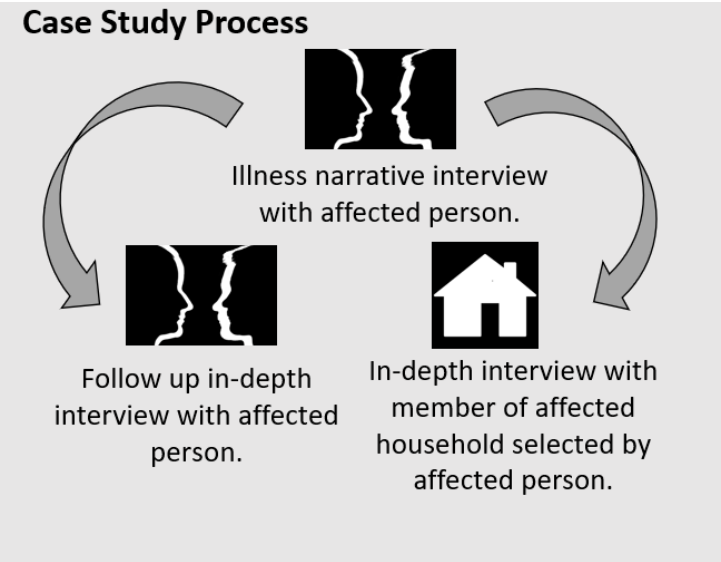
7.4 Methods

Situated within the naturalistic paradigm of qualitative research enquiry(Baum, 1995, Pluta et al., 2015), narratives seek to redress the dominance of biomedicine within research on health inequities by exploring the impact of multiple structural and social oppressions on health and wellbeing from the vantage point of the most

marginalised(Bowleg, 2012, Christensen and Jensen, 2012). By using everyday life as an entry point, narrative approaches resituate the human as a storyteller best placed to recount their own reality of suffering and resilience (Christensen and Jensen, 2012, Mendenhall, 2016). Additionally, narratives can support individuals to make sense of their illness experience(Mendenhall, 2016) in relation to varying and interconnected social categories and identities(Prins, 2006). Thus, narratives are a useful tool both in advancing syndemic theory(Mendenhall, 2016) and in intersectional research(Christensen and Jensen, 2012).

We used a case study method to explore illness experience from the perspective of individuals living with clinical manifestations of one or more of the identified NTDs (Figure 12). In addition to these narrative interviews, to complete case study sets, semi-structured interviews were completed with household members as within NTD literature there is evidence to suggest that suffering in relation to NTDs (specifically leprosy) has impact at the household level(Barrett, 2005, Litt et al., 2012). Case studies were complemented with the use of key informant interviews to ensure further consideration of the broader socio-political context in relation to NTDs and mental distress in Liberia.

Figure 12: Case Study Process



7.4.1 Study Setting and Disease Focus

We collected data in three purposively selected counties: Maryland, Nimba and Bong. Selection criteria included: 1) all diseases are endemic; 2) geographical and socio-cultural diversity; 3) differing levels of health systems infrastructure; and 4) pilot sites for the roll out of the Liberian Ministry of Health's strategy for the integrated case management of NTDs. Within each county, we further purposively selected study district(s) (one in Maryland, one in Bong and three in Nimba) based on NTD-associated morbidity identified from health records. Maximum variation across all study districts was aimed for in geography (rural/peri-urban, border/non-border) and socio-cultural context (ethnicity and language).

Liberia's integrated case management plan for NTDs focuses on Leprosy, BU, Yaws and the clinical manifestations of LF (lymphoedema and hydrocele)(Ministry of Health, 2016). In this study, we focused on Leprosy, BU, lymphoedema and hydrocele. Onchocerciasis was also included due to the large numbers of persons affected by chronic morbidity as a result of high disease endemicity in Liberia. Yaws was excluded because when the study commenced cases of yaws were not yet confirmed in Liberia.

7.4.2 Participants and Sampling Procedure

Illness Narrative Case Studies: We generated a sampling frame of all potential participants from health systems records and tacit knowledge of health workers. We then purposively selected participants to ensure maximum variation, considering age, gender, and experienced morbidity as core sampling criteria. However, as case studies were generated we ensured that further diversity in the biological and social conditions of participants was achieved; this was in response to reflection participant descriptions of their lives both pre and post illness and researcher observation of the broader environment where participants resided. Table 7 provides an overview of the case studies completed and Table 4 (4.7.4) gives a summary of each case study. To identify household members to include in case studies affected persons were asked to identify someone of significance in their daily lives that we could also talk too. Case study data collection continued until data inductive thematic saturation

was reached; that is when core analytical themes became repetitive and emergence of new themes or ideas infrequent (Saunders et al., 2018).

Table 7: Summary of Case Studies Completed

	Age	LF (Lymphoedema /Hydrocele)	BU	Onchocerciasis	Leprosy	Total	
Men	**18-24**				2	**2**	**13**
	25-49	1	2	1	2	**6**	
	Over 49	1		2	2	**5**	
Women	**18-24**		2			**2**	**13**
	25-49	3	2	1	1	**7**	
	Over 49			1	3	**4**	
Total		**5**	**6**	**5**	**10**	**26**	

Key Informant Interviews: We conducted thirteen individual and one paired semi-structured interview with key informants at the national and county level. Table 8 provides an overview of issues explored, key informant type (purposively selected based on their job role) and their health systems function. A priori thematic saturation was achieved within key informant data as the purpose for key informant inclusion was to ensure clearer understanding of the socio-political context in relation to NTDs, disability and mental ill-health (Saunders et al., 2018).

Table 8: Key Informant Characteristics and Issues Explored

Key Informant Type	Role in Health System	Number Included	Issues Explored
NGOs or Donor Representative	Provide programme funds and technical support to implementation through the same organisation.	2	-Disability -Mental Health -NTDs -Generation, content and implementation of Integrated Case Management Plan -Programme strengths and challenges
National Ministry of Health Staff (NTD Programme)	Oversee NTD policy development and programme delivery.	4	
National Ministry of Health Staff (Rehabilitation Department)	Oversea rehabilitation policy development and service delivery.	1	-Disability -Mental Health -NTDs -Vignettes developed from narrative case studies presented to explore participant reactions to experiences and develop holistic solutions.
National Ministry of Health Staff (Mental Health Department)	Oversea Mental Health policy development and service delivery.	1	
Disabled People's Organisations	Civil society organisation aimed at promoting collective action amongst disabled persons and rights advocacy.	2	
Ministry of Health County Health Team (NTDs and Mental Health Focal Points)	Support the implementation of NTD programme and mental health service delivery at county level.	1	

7.4.3 Data Collection Process

Data collection took place between January 2017 and June 2018.

Illness Narrative Case Studies: Initial narrative interviews with affected persons took a highly unstructured approach to questioning to allow for subjective reflection(Pluta et al., 2015). The initial interview strategy drew on life history approaches to understand participants' background(Wurie et al., 2016). This involved giving

participants the space to speak freely about key events in their lives(Mendenhall, 2016), before encouraging them to focus on illness experience linked to NTDs(Thomas et al., 2009). We guided participants to consider areas of participation, as guided by the international classification of functioning(World Health Organization, 2001).

The purpose of household member interviews was to gain additional understanding of the experience of affected persons and household impacts within the broader social context. Therefore, a semi-structured approach was used to guide participants through multiple and diverse topic areas within one interaction(Ritchie et al., 2013). Interviews explored: knowledge and perceptions of disease and/or disability (including mental ill-health); impact of the disease on the individual and household (including relationships, daily routine, economics, community interactions); and possible support interventions.

7.4.4 Ethical Considerations

Written or witnessed verbal informed consent was obtained from all participants. Ethical considerations are discussed in detail in (Dean et al., 2019b). Supporting the wellbeing of participants was prioritised throughout, which involved ensuring appropriate medical and psycho-social support was provided where required. Names used in presenting the data are pseudonyms.

7.4.5 Data Analysis

The primary focus throughout analysis was to privilege the voice of affected persons and other members within the household. Analysis drew on the use of thematic analysis, as well as analytical steps that allowed for the holistic consideration of case studies, since both narrative and intersectional analysis require holistic consideration of stories in relation to the broader socio-political context(Thomas, 2010). Analysis was ongoing throughout the data collection period, including: critical reflection of emergent issues and themes during the first interaction with participants; re-listening to initial interviews; and design of questions to explore key themes and emergent issues in subsequent interviews and additional case studies. All transcripts (which were transcribed verbatim into English) within a case study were used to

develop a summary of the case study. Key threads and themes within each narrative were identified and considered in relation to the broader temporal and social context. From these summaries a very broad coding framework was developed and used to explore links and patterns across narratives(Pluta et al., 2015). We applied this coding framework to the data (using NVIVO 11 software), and charted data into broader themes to develop an explanatory account (Ritchie et al., 2013). Key informant interviews were also analysed thematically and charts from the different data sources brought together at explanation stage.

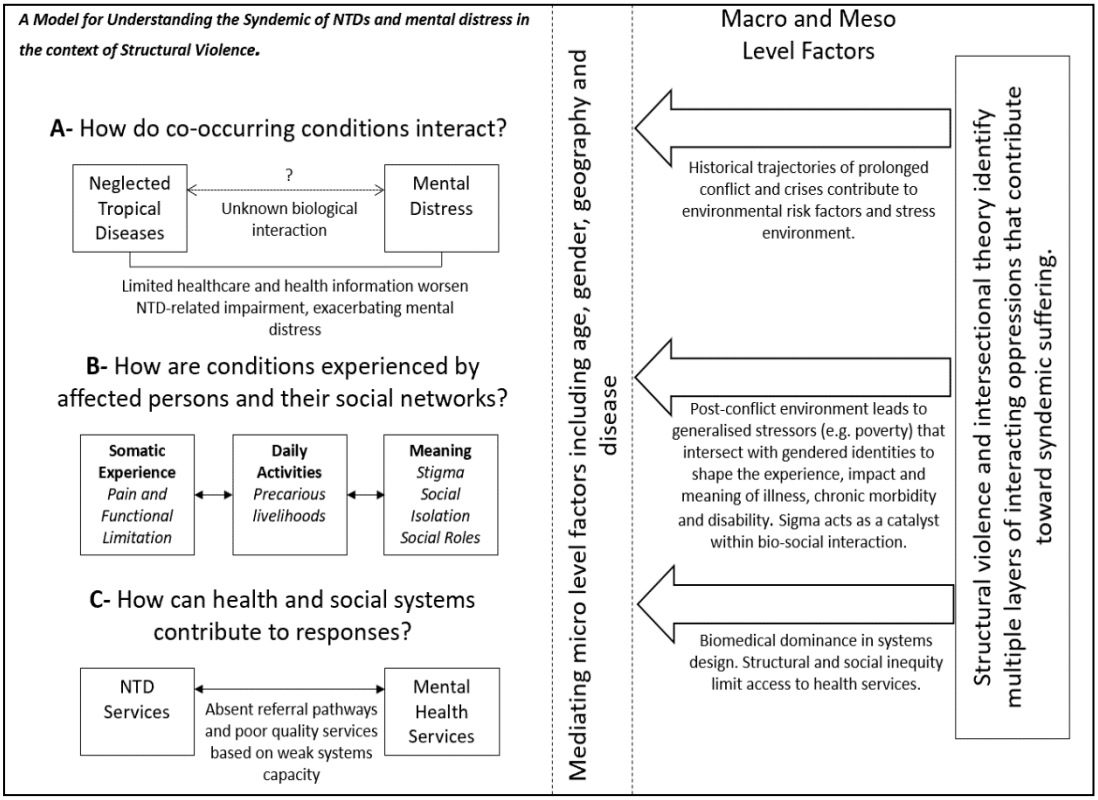
We used theories of structural violence and intersectionality to inform analysis and support triangulation across methods to understand how the syndemic of NTDs and mental distress is shaped by intersecting factors at the macro, meso and micro level (Simpson, 2009). We draw on both intra- and inter-categorical intersectional analysis as we explore experiences of specific sub-groups within the larger group of people affected by NTDs whilst also exploring the complexity and relations between multiple categories of inequality(McCall, 2005). In generating explanatory accounts of data, Mendenhall et al. (2017) model for syndemic approaches to health was applied and adapted as presented in Figure 13. This enabled discussions around meaning and linkages within our data as well as group reflections on appropriate health systems responses.

7.5 Findings

Our findings present our adaptation of Mendenhall et al. (2017) 'Model for Syndemic Approaches to Health' (Figure 13) to present evidence of a syndemic relationship between NTDs and mental distress in the context of structural violence in Liberia. Stigma is described as a key structural mechanism through which this syndemic interaction is promoted(Singer et al., 2017b). Intersectional theory becomes critical in shaping understandings of how historic forces of power and oppression (that underlie structural violence) interconnect to contribute toward 'syndemic vulnerability'. Specifically, intersectionality allows for consideration of how individual positionalities within a web of intersecting inequities shape how the stress environment becomes embodied in individual experiences of syndemic suffering

(Figure 13, Section B). Our analysis revealed multiple multi-level pathways through which structural violence shapes vulnerability to NTD infection, chronic morbidity/disability, and mental distress in ways that reinforce each other. We discuss these in turn in the following sections as they are represented in Figure 13.

Figure 13: A Model for Understanding the Syndemic of NTDs and Mental Distress in the Context of Structural Violence.



Before exploring the syndemic, we first introduce two stories that emphasise the suffering endured in relation to NTDs and mental distress in Liberia. Both Jon's Story (Box 6) and Hannah's Story (Box 7), characterise the lived reality of syndemic suffering by highlighting how larger structural socio-political processes such as protracted conflict and poverty (macro) and resultant weak health and social systems (meso) have created **general stressors** (figure 14) that particularly affect people living with NTDs, (as a minority status), creating a risk environment for exacerbated physical morbidity and mental distress. **Internal and external minority stressors** (figure 14) related to stigma and discrimination (meso-micro) as a result of NTDs, catalyse a synergistic interaction between NTDs and mental distress that are further

shaped by household and individual (micro) level characteristics that **shape minority identity** (figure 14), such as gender and generation, to create nuanced experiences of syndemic suffering.

Box 6: Jon's Story

Jon, 46, was a teacher and had documented his story in chalk on a wall in his house.

In 1985, Jon experienced severe itching and sought treatment at the hospital. He was given Banocide (historic treatment for onchocerciasis), describing '*They cut my skin at that time and told me it was filaria…inside plenty. [The medicine] worked - my skin could not itch'*.

In 1990, the itching started again but he could not reach the health centre to access medicines because of conflict and fighting.

In 2005, Jon was desperate to continue working, so he began health seeking again. Firstly, he went to the hospital, but was told there was nothing they could do. Next, Jon went to see an old lady in the community who gave him 'bitter root' to manage the itching.

In 2012, Jon travelled to a bigger hospital where he was told he had glaucoma and then cataract and needed surgery. He was given medicines to reduce his blood pressure, which 'didn't work', so the surgery was cancelled. The high costs of health seeking and medicines meant Jon could no longer afford them and returned to his community.

The mectizan distribution programme (mass treatment for onchocerciasis) came to Jon's community. Some distributors were charging for the medicines, but Jon went to their house and demanded free medicine. He still couldn't see *'the wall'* properly; he decided to go back to the hospital. He was told it was filaria and given some more medicines.

Jon described that *'even when I took that medicine now my whole body [is] scratching'* and his sight was still worsening. Word had spread in the community that he was going blind until the last entry on the wall where he told us: *'I feel hurt when I open [my eyes]and I can see no writing. Hmm I can see no writing'.*

Jon described how his wife had left him and taken their children to live in another community. He found being alone in the house challenging as he struggled to find food and couldn't fix the leaking roof. He told us: *'I just sit down the whole day. You [are] alone and you know what it means'.* Describing his last chalk marking and going blind as the end of his journey, he felt isolated and alone and didn't see the point in living anymore.

Box 7: Hannah's Story

In 1991, as a teenager, Hannah started to experience severe itching on her skin and 'tears were coming from her eyes' when she looked at the light. Liberia was in conflict and health seeking was difficult. Hannah's mother sought care for her daughter in Guinea and Ivory Coast where she accessed traditional medicines, before finally reaching a hospital in Liberia where she was given Filaria medicine. She was told to return to the facility when the medicine ran out, but health seeking was expensive. They asked for support from the community to return to the hospital but it was the end of the war and people were reluctant to share the little money they had.

In 1994, Hannah described that she woke up '*noticed that I couldn't see my parents again, I started telling them I can't see, I can't see, [I] was looking all around for things from beside [me], [I] was looking for something to just finish [my] life.'*

Since 1994, Hannah described that *'men will come and tell me they will help me, but after a period of time, they leave'.* Hannah has given birth to four children but has sent them to her sister as she and her mother struggle for food. Contribution to the household is difficult for Hannah, and her siblings often exclude her and tell her that they have their own children to look after. Hannah's mother is her primary carer, however Hannah feels a burden and is worried *'who will take care of me, when my mother dies'*.

Hannah described how taking medicine for Filaria had helped her skin to stop itching. However, she said she still struggles to move around in the community as she feels *'afraid'* and *'ashamed'*. Her toilet is far from the house, so she must defecate just behind the house so as not to move too far.

Hannah's mother described that she used to go regularly to church, but since her daughters' sickness *'I] can't go nowhere to leave her...'* When asked why, she explained: *'because Hannah [is] always saying she will kill herself. So, [I am] afraid maybe if [I] go out, she may come and take something to harm herself.*'

7.5.1 A- How do the social-psychological processes of co-occurring conditions interact?

To the best of our knowledge, the biological interactions between NTDs considered in this manuscript and endemic to Liberia (onchocerciasis, leprosy, Buruli ulcer, lymphoedema, hydrocele) and mental distress have never been considered. Furthermore, no studies in Liberia, and few internationally, have interrogated epidemiological overlap(Litt et al., 2012, Mousley et al., 2014, Ton et al., 2015). Where epidemiological overlaps have been considered, rates of mental distress amongst people affected by NTDs have been shown to be higher than in the general

population(Mousley et al., 2014, Alem, 2004, Erinfolami and Adeyemi, 2009). A study in Ethiopia found that people with lymphoedema (as a result of podoconiosis) scored 1.43 points higher [95% CI:0.52 to 2.34] on the Kessler psychological distress scale than healthy neighbourhood controls(Mousley et al., 2014). High rates of depressive disorders were also found amongst people affected by filariasis in Togo (70%)(Richard et al., 2007) and India (97%)(Suma et al., 2003), and estimated between 12.5% and 76% among various leprosy affected populations(Alem, 2004, Kisivuli et al., 2005, Nishida et al., 2006, Su et al., 2012, Verma and Gautam, 1994). The reverse correlation has not been considered, however it is hypothesised as based on overlapping risk factors such as poverty, social exclusion, and poor living conditions(Litt et al., 2012, Mousley et al., 2014).

Data on mental health and NTDs in Liberia is lacking due to a lack of research and weak surveillance systems(Ministry of Health, 2016, World Health Organization, 2017). Available data shows that following the conflict in Liberia there is a high burden of mental ill-health with 40% of the population self-reporting symptoms consistent with major depression, and 44% of the population describing symptoms common with or experience of post-traumatic stress disorder(PTSD)(Johnson et al., 2008). PTSD symptoms have also been documented to have a longer term impact than is typical due to the extent of violence experienced during Liberia's conflict and the protracted experience of material deprivation(Galea et al., 2010). Simultaneously, the ongoing context of poverty, poor environmental conditions (including inadequate water and sanitation infrastructure), low levels of literacy and weak health service provisions means that many Liberians are vulnerable to NTDs and their associated chronic morbidities (Thomas et al., 2017, Hotez et al., 2016). Although exact burdens are unknown, due to a lack of case reporting and identification, the Liberian Ministry of Health, has identified that NTDs, particularly those manifesting in the skin, present a substantial disease burden (Ministry of Health, 2016). Following the first year of integrated active case detection for the NTDs of focus in this study, diagnosis and detection rates rose dramatically; for example, the number of health system reported cases rose from 44 to 327 (439% increase) in Maryland county alone(Ministry of Health, 2018). Patients accessing

treatment for the first time were identified as presenting in the latter stages of disease. For example, at the point of diagnosis there are high rates of grade 2 disability amongst persons with leprosy and 100% of persons with confirmed Buruli ulcer present with ulcerative lesions(Ministry of Health, 2018). There is a growing evidence base from other settings regarding co-morbidity between skin NTDs and mental ill-health(Bailey et al., 2019, Litt et al., 2012), and an apparent co-occurrence of these two epidemics within Liberia.

This epidemiological evidence thus suggests co-morbidity between NTDs and mental distress, but further study of biological interactions would be required (Singer and Clair, 2003). We have not explored biological interactions between disease conditions; rather we seek to shed light on the social and structural mechanisms through which mental distress and NTDs synergistically interact to create exacerbations of health disadvantage. Our analysis shows that the historic and social context of war in Liberia contributes to the production of multiple 'generalised stressors' or risks (Figure 13) that promote the existence of these co-occurring epidemics(Meyer, 2003).

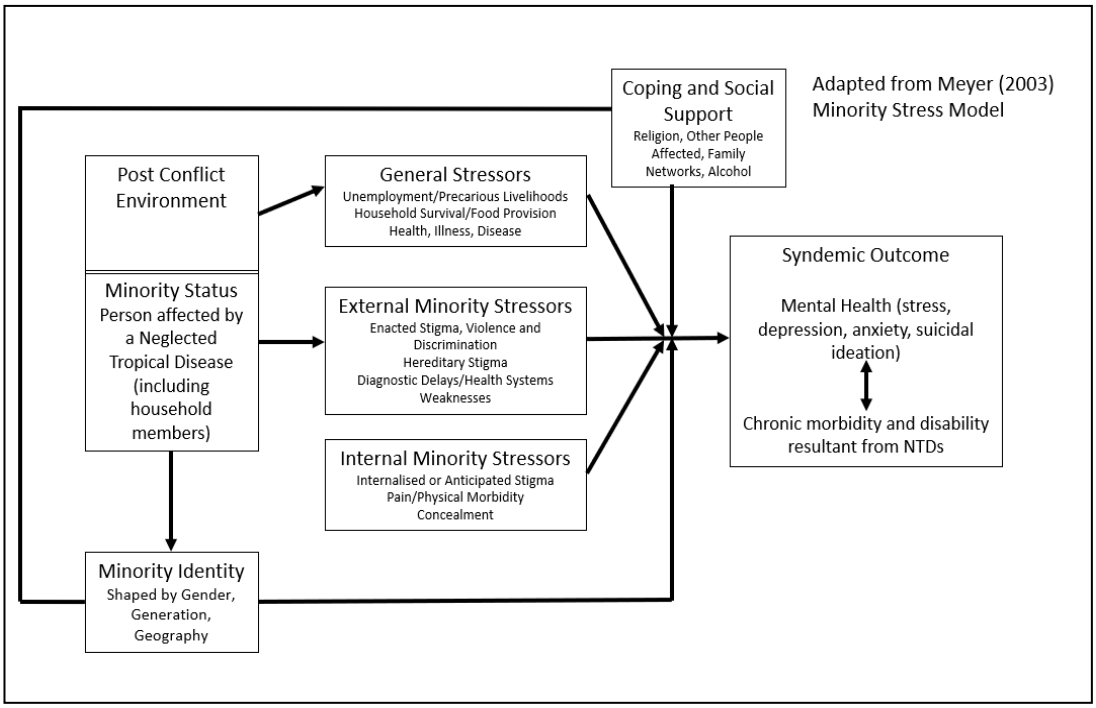
We used NTDs as an entry point to explore the relationship between these co-occurring epidemics; however using mental health as an entry point in encouraging participants to share their stories could also support in understanding if the interaction between these two epidemics is bi-directional (Tsai, 2018). Data presented here can only support a unidirectional interaction by which chronic morbidity and disability associated with NTDs (particularly poor access to information and care) contribute toward periods of mental distress, catalysed by experiences of stigma in the context of structural violence. However, other research studies in Liberia and elsewhere in sub-Saharan Africa have shown that delays in generalised health seeking as a result of mental ill health are common due to stigma, financial constraints, and lack of knowledge of illness(Andersson et al., 2013, Thornicroft et al., 2016, World Health Organization, 2017). Lack of management of mental ill-health has been described as exacerbating these delays; this is common in Liberia due to ongoing health systems weaknesses(Johnson et al., 2008, World Health Organization, 2017) (further discussed in section 7.5.2- B and 7.5.3- C). Thus, based

on shared environmental risk factors and micro level stressors, including dual stigmatisation, it is likely that these co-occurring epidemics may have a bi-directional interaction. This would align with evidence from other syndemics where depression is frequently cited as a key element that can worsen health and wellbeing outcomes of chronic illnesses (Singer et al., 2017a).

7.5.2 B- How are the conditions experienced by affected persons and their social networks?

As suggested by Mendenhall et al. (2017 p953) within syndemics *'culture shapes meaning associated with suffering and social responses to suffering, illness and disability'*. Within this section, we draw on and adapt Meyer (2003) 'minority stress model' (see figure 14) to emphasise the critical role of stigma in promoting the synergistic interaction between NTDs and mental distress. Firstly, we suggest that the post-conflict environment presents multiple 'generalised stressors' as a result of structural violence that may contribute to periods of mental distress. For people affected by NTDs (who we argue have a 'minority status' due to experiences of disadvantage)(Meyer, 2003), we hypothesise, based on our data, that these 'generalised stressors' are exacerbated. However, the degree of exacerbation is also dependent on the impact of intersecting power relations such as gender, generation and geography that shape individual identity and resilience. As has been found in relation to other chronic conditions, we specifically consider how the mutually reinforcing interactions between somatic experience, ability to complete daily activities and the social meaning of disease (social isolation) can shape experience(Mendenhall et al., 2017). Secondly, we consider how both 'external and internal minority stressors'(Meyer, 2003), specifically varying processes of stigmatisation and discrimination, become additive to 'generalised stressors' to produce an excess risk of mental ill health amongst people affected by NTDs due to social stress which is resultant from social and structural inequities(Meyer, 2003). Finally, by considering how both 'generalised' and 'minority stressors' become embodied in different ways based on intersecting axes of inequity such as gender, generation and geography we can consider how internalisation of oppression functions in different ways to shape nuanced experiences of the syndemic.

Figure 14: Adapting Meyer (2003) Minority Stress Model to Emphasise the Catalytic Role of Stigma in Shaping Syndemic Outcomes for People Affected by NTDs



7.5.2.1 General Stressors

The following three sub-sections explore descriptions of how experiences of general stressors emerging from narrative accounts were shaped and exacerbated by minority status and identity and contribute to the impact of negative health outcomes.

7.5.2.1.1 Pain, poverty, precarious livelihoods and financial stress

Physical limitations associated with NTDs have been described as a key pathway for their contribution toward poor mental health due to lost job opportunities, and dependency on others (Person et al., 2007, Mackenzie et al., 2009, Krishna Kumari et al., 2005); however, this has infrequently been considered in relation to its impact on gendered social roles and the broader economic environment. Within narrative accounts, precarious livelihoods that centred around day to day survival (often a combination of strategies including subsistence farming, selling, and fishing), coupled with individual's inability to fulfil expected gendered social roles (e.g. as a wife, mother, husband or father) were a key focus and trigger of stress. Somatic experience, including variations in pain and functional limitation experienced at

different time points, and changes in physical appearance, contributed to the impact of illness on livelihoods. For some, restrictions in mobility and alterations to physical appearance were permanent whilst others described these as more transient or temporary and triggered by specific activities or social situations.

For women and men affected, the degree of independence in completing livelihood activities was a key determinant of the level of stress experienced. Many individuals would struggle through daily activities to reduce negative impacts on the household and to complete their role as a wife, mother, husband or father. For example, for persons affected by BU, particularly women, having to complete livelihood tasks that involved use of the affected area or limb frequently triggered pain and mobility restriction. Alice, who had ulceration on her legs, *'had no one to do things for me'* and so *'when I was walking long distances, I can feel [pain]…but I have to force it to get my daily bread'* **(CS017, Female, BU, Nimba).**

For some people with lymphoedema, restricted mobility linked to physical impacts of disease and associated stresses was explicitly linked to the experience of acute attacks. During acute attacks, the impact on households and associated stresses were exacerbated, particularly when participants felt gendered roles and responsibilities within the household were compromised. For example, Natt, described that during these periods there was a heavy load on his wife; he found this particularly difficult and demasculinising as he was not able to fulfil his role as a husband during these periods and it is not what should be expected of him *'at his age'* **(CS008, LF, Male, Maryland)**. By subconsciously trying to live-up to patriarchal advantage and fulfil a position of 'hypermasculinity', which is highly resonate in Liberia as a result of protracted conflict(World Health Organization, 2017), both Natt and Jon experienced stress or isolated themselves socially as a coping mechanism. However, as particularly exemplar in Natt's case this stress was not static; rather, the interplay of disease severity and ability to fulfil gendered ideals mattered. For Jon and Hannah, and others alike, protracted negative impacts on their livelihood activities coupled with social isolation and stigmatisation had resulted in extremely poor living conditions, leaving them vulnerable to additional health and social risks, including for Hannah fear of gender based sexual violence.

7.5.2.1.2 Stress, Social Isolation and Challenged Gendered Identities

In some cases, for example in Jon's story (Box 6), inability to complete tasks 'expected of a man' had led to men being left by their spouses and isolated from children and other family members. This appeared to be less linked to illness origins and more to the severity of illness and/or permanency of impairment. Conversely, the onset of illness had caused some men to worry that they may not be able to find a spouse because of illness. However, this was often not the case, with some men marrying and having children post illness.

Many young women, had similar experiences to those described by Hannah (Box 7) and had been left by an intimate partner, or approached for sex and then abandoned when they became pregnant. For some women, particularly those living with lymphoedema and onchocerciasis this was a repetitive pattern, where men would approach them during periods where the 'leg was small' however following acute attacks they would be abandoned. For Hannah, and others alike, desire to fulfil gendered identities of motherhood frequently led them to make choices which presented them as vulnerable to inter-personal relationships that were challenging; this emphasises how social constructions of gender can influence women's agency in decision making(Mendenhall, 2016).

Women who also constructed their identity around motherhood, felt a sense of sorrow as they were often unable to care for their children as they would have liked and therefore many children were living with other relatives or, in some cases, mothers felt they were not receiving the care they needed. Social isolation because of illness particularly from the natal family was linked in narratives to a shift from being able to contribute to household livelihoods to becoming a dependent. This was particularly true for male participants, suggesting a link between prescribed gender roles and social isolation coupled with challenges to economic circumstance.

> *'if I complain about the sore they will feel that I want money from them…. I feel bad, we supposed to be together, joke together, play together as a human being...**(CS026, Male, BU, Bong)**.'*

7.5.2.1.3 Health stress, social and structural barriers

Jon and Hannah's stories are illustrative of many narrative accounts that emphasise the stress that barriers to health care access brought to participants both during the conflict and more recently. As described in these two stories, failure to access essential services due to conflict, lack of financial resources, and stigmatisation by health workers was often seen to result in life altering physical morbidity.

Within narratives where participants had become sick post-conflict, multiple care seeking visits were a dominant narrative thread and source of stress, with participants describing ongoing oscillation between formal and informal health providers in constant search of a diagnosis or cure for an often-unknown disease condition. Being unable to understand the cause of their impairment or poor physical health was often described as distressing for participants (Dean et al., 2019b). Repetitive health seeking was often necessary as a result of weak health system capacity to be able to diagnose or identify cases due to: poor knowledge amongst health care personnel; limited supplies and weak laboratory systems that restricted health worker ability to confirm cases and initiate treatment, particularly for BU; and a shortage in medicine supplies, especially when medicines are not freely donated without laboratory confirmation. Where medicine supplies were limited, health workers reported having to make decisions about who to provide medicines to, rendering some individuals without access to treatment, thus exacerbating morbidity.

> *'sometimes you have four or five cases, sometimes you will only have treatment for two person and the drugs are not on time...'*
> ***(KII006, County NTD Focal Point)***

The necessity of repetitive health seeking brought further financial stress and strain to individuals and households and many individuals resorted to seeking alternative care, predominantly within the 'traditional health system'. The traditional health system was also frequently cited as a first point of call for many people due to their syncretic perception of disease origins not considered in the formal health system,

and a trust in the traditional system because of community proximity and stability during periods of fragility(Kruk et al., 2011).

Stress associated with precarious livelihoods, social isolation and weak health systems infrastructure represents a conflux of political-economic and social inequalities. Particularly evident within narrative accounts of stress was the ways in which individuals have internalised the social domination to which they are subjected based on gendered identities(Mendenhall, 2016); this process has been described as symbolic violence (Mendenhall, 2016) due to its contribution toward poor health outcomes. By applying framings of both structural and symbolic violence, coupled with intersectional thought, we can consider how general stressors (see figure 14), as a result of social and structural inequities, become embodied in multiple and alternate ways to shape unique and contextualised experiences of syndemic suffering.

7.5.2.2 Stigma: Internal and External Minority Stressors

In the subsequent three sections we discuss 'types' of stigma identified within the framing of Scambler (1998) hidden distress model of stigma. This presents critical distinctions between stigma which is actually experienced ('enacted') and that which is 'felt' (either as a result of anticipation of enacted stigma or that which becomes internalised)(Scambler, 1998, Weiss, 2008). These experiences become a product of the wider social and structural context in relation to health and illness and can be described as internal or external 'minority stressors'(Meyer, 2003) (see Figure 14). We argue that it is these 'minority stressors' that exacerbate or are additive to 'general stressors' as stigma associated with these illnesses, coupled with the stigmatised identities of people affected by them, become a critical driver in shaping the interaction between mental distress and NTDs in Liberia(Singer et al., 2017b).

7.5.2.2.1 Enacted Stigma (External Minority Stress)

Stigma was commonly described as a reason for experiences of violence and as has been documented in other settings, was a driver of mental distress associated with NTDs (Hotez, 2008, Litt et al., 2012, Weiss, 2008). Mary (CS018) described that her experience of enacted stigma (through verbal insults) in the community made her

husband very angry and led him to leave her at the leprosy hospital. Although she described her husbands' actions as based in love for her, this revealed a lack of autonomy or control by Mary in decision making, based on underlying gendered powered hierarchies, which contributed towards her experiencing emotional distress and isolation. Stigma in Mary's case became a key driver through which leprosy and mental distress became interconnected and mediated through her identity as a woman to threaten her health and wellbeing.

> *'My husband, he sent me to the colony…he never gave me any cross word; but people who live in the community they are the people who were insulting me. They made the man vex (angry) to say ''I will take my woman to medicine…". Then at that time then I began to cry. He said, "don't cry I will send you to medicine man; I will carry you."'* ***(CS018, Female, Leprosy, Nimba).***

Case study narratives related to leprosy and BU, revealed a complex relationship between in-patient treatment, religion, enacted stigma and psycho-social well-being. For many, in-patient treatment as a result of being around other patients provided a sense of comfort and social support, and where in-patient treatment was provided through faith-based organisations religion often provided additional relief. Regardless of treatment location, faith was particularly pivotal for affected persons during periods of depression or when experiencing suicidal thoughts, as the illness was felt to be part of *'god's plan'*.

> *…when your life story change, it looks bad…I even decided to kill myself but then God just made a way…That's how my life became...I used to think about killing myself; now, I say it was good I didn't do anything to myself because that's god will'* ***(CS012, Male, Leprosy Patient).***

Despite the positive benefits of in-patient treatment and the critical role and introduction of faith as a coping mechanism for many affected persons, both historic and ongoing in-patient care had impacts on the ability of some leprosy and BU patients to re-integrate with their communities. Some persons affected by leprosy

narrated that even when they had completed treatment and were no longer infectious, the community would still see them as sick, feeling that; *'even if we received treatment for eight years, nine years, leprosy can't finish (CS009)*'. Isolation and rejection from their communities often had significant negative impacts on affected persons mental well-being.

7.5.2.2.2 Hereditary Stigma (External Minority Stress)

Hereditary stigma(Goffman, 2009, Weiss, 2008) was also commonly experienced, frequently leading to social isolation of the household from the broader community. Joy's sister described how since her sister had returned from in-patient treatment for leprosy her '*own friends don't want to come here [to the house]'* ***(CS011, Nimba)***. Princess also described similar experiences of hereditary stigma within inter-personal relationships that meant she now kept her father's illness to herself where possible.

> *'because they [my friends] didn't know my father's condition, nothing bad they can tell me to make me feel bad [they are nice to me]. But because the man…the man who can asked me where my father is, and I told him about my father…the problems can be there [he is unkind because he knows about my father]…'* ***(CS012, Princess, Nimba).***

Threats to inter-personal relationships for many women in relation to some NTDs has been considered elsewhere(Person et al., 2007, Vlassoff et al., 2000), however the impact at household level is seldom described. Where multiple people within one household were sick, social isolation and separation were exacerbated. However, for older participants, stigmatisation and associated isolation was described to a lesser extent based on the perception that getting sick in old age was seen as inevitable.

7.5.2.2.3 Internalised or Anticipated Stigma (Internal Minority Stressors)

Many participants, particularly women, although some men, also showed signs of internalised or anticipated stigma(Goffman, 2009, Weiss, 2008), describing that they felt ashamed to expose body parts in public. These behaviours have been described elsewhere in relation to NTDs, particularly when impairment was acquired in

adulthood based on the fact that prototypes of health and normalisation were often learned from a young age(Barrett, 2005). This was also true within our study. Some women described wearing longer 'lapper' to cover limbs so that they weren't exposed or visible when moving around in public, men described wearing '*loose and long trousers, so that people won't know until they open it'* **(CS026, Male, BU, Bong)**.

As well as adjusting their behaviour, many participants described that they would *'sit and think'* or be *'thinking too much'* as a result of physical morbidities and social responses to their disease condition. Many participants also described withdrawing themselves socially as a result of stigmatisation, and a few participants also described a dependency on alcohol during periods of isolation as a coping strategy, thus presenting them with further vulnerabilities to additional risks such as violence.

> *'Myself when it happened to me I was thinking too much so I nearly I was a drunk on the street, I will not lie.'* ***(CS012, Male, Leprosy, Nimba)***

Phrases such as *'thinking too much'* have been identified in other sub-Saharan African settings as being 'idioms of distress' used to communicate psycho-social ill-health(Avotri et al., 1999). A study in Maryland, Liberia, identified two categories of idioms of distress; those related to the mind and brain and those related to the heart (Fabian et al., 2018). The authors present '*thinking too much'* as a brain idiom that is closely related to heart related terms but which extends beyond everyday experiences of sadness to describe mental distress that can lead to stigma and discrimination(Fabian et al., 2018). Descriptions of these idioms of distress within narrative case studies suggest evidence of co-occurrence of NTDs and mental distress. Stigmatisation (enacted, hereditary, internalised and anticipated)(Goffman, 2009, Weiss, 2008) plays a critical role in driving the interaction between biological and social and structural processes or stresses that threaten health; thus indicating evidence of a stigma syndemic(Singer et al., 2017b).

By facilitating an analysis of the ways in which stigmatisation intersects with factors that shape individual identity (e.g. gender and generation) to form varying pathways of bio-social interaction, intersectional theory has the potential to significantly add

to the existing literature on stigma syndemics. Understanding how intersecting power relations shape the way that stigma becomes transformed from a social phenomenon into a force that can create devastating health outcomes is critical in being able to shape adequate social and health systems responses(Meyer, 2003, Singer et al., 2017b). Some argue that the role of stigma in illness experience linked to NTDs is overplayed often at the expense of other factors that can lead to social isolation and consequent mental distress(Ribera et al., 2009). However, as has been highlighted in relation to other syndemics that are promoted through structural and social processes of stigma and discrimination(Singer et al., 2017b), we propose that the experience of stigma in relation to NTDs and mental distress may warrant consideration within a syndemic model in other settings.

7.5.3 C- How can health and social systems contribute to responses?

We have shown how health systems failures and social and structural inequities contribute to experiences of syndemic suffering. Within the following section we focus on the implications of syndemic analysis for ways forward. Liberia's health system is undergoing a period of reform and national priorities reflect a shift toward more integrated health service delivery to ensure efficient use of scare resources(Ministry of Health, 2015a). Integrated, people-centred health systems are increasingly recognised as more effective in responding to the health needs of populations, particularly those in low income settings, and draw on ideals of 'syndemic care' by ensuring the advancement of treatments and interventions that respond holistically to broader social and structural inequalities that shape disease interactions and create ill-health (Mendenhall et al., 2017, Mendenhall et al., 2015, World Health Organisation, 2015). Thus, person-centred approaches that are grounded in syndemic understandings of disease and illness offer an optimal framework for informing the type of multi-level responses that are required to improve individual and population health outcomes in Liberia.

Our findings emphasise that the social world of our participants cannot be disconnected from their experiences of NTDs and mental distress; thus, health systems must be able to respond to both the social and psychological dimensions of people's lives to be able to successfully manage NTDs(Mendenhall, 2016). By using a

syndemic framework to consider how social and structural stressors shape impacts on health, it is apparent that NTDs and mental distress in Liberia require multi-sectoral responses, which require further investigation and research. Intervention approaches that focus on the cause of suffering, such as by addressing stigma or livelihood needs are therefore essential in improving the health and wellbeing of affected populations in Liberia. 'Stepping Stones' is one example of a gender transformative community-based participatory learning programme focused on HIV that aims to minimise the contribution of power hierarchies in shaping negative disease interactions (e.g. between HIV, Gender Based Violence and Mental Distress) and stigmatisation (Jewkes et al., 2008, Paine et al., 2002). By focusing on community norms and values, such approaches are in line with people-centred responses to ill-health as they are adaptive to the contextualised experience of suffering at the community, household and individual level. Participatory processes of adaptation and learning similar to 'Stepping Stones' could support in the design and delivery of 'syndemic care'(Mendenhall et al., 2017) in relation to NTDs and mental distress in Liberia.

Putting people and their values at the centre of health intervention design is a key underlying principle in people centred health systems(Sheikh et al., 2014b). Intervention responses must therefore be mindful of medical syncretism and pluralistic health seeking, especially since our study supports other studies in Liberia emphasising that the traditional health system is widely consulted during periods of psycho-social distress(Kruk et al., 2011, Kruk et al., 2010). The current absence of collaboration between the traditional and formal health system in relation to NTD management delays health seeking and exacerbates physical morbidity. Despite challenges of collaboration with the traditional health system in other sub-Saharan settings due to the 'paradigmatic disjunctures' and uncertainty between varying treatment approaches, successful partnerships have been achieved in the presence of mutual respect and through collaborative intervention design (Ae-Ngibise et al., 2010). Actors in the traditional health system could be important partners in responding to the syndemic interaction between NTDs and mental distress in Liberia.

Prolonged conflict and post-conflict fragility have resulted in an inaccessible and under-resourced health system in Liberia, with very limited specialist services. As a result, two key challenges remain in providing responses and treatment for synergistic interactions between NTDs and mental distress; 1) identifying patients and 2) health workforce limitations. Tasking and training community health volunteers to support early case identification is a key strategy to mitigate this barrier to diagnosis within integrated case management plan and has proven to be effective for BU in other endemic settings(Corley et al., 2016). However, as with many community health interventions, key Informants described ongoing challenges in the referral of patients due to accessibility barriers (geographical and financial), stigmatisation and attrition of community health volunteers due to lack of incentives in the context of precarious livelihoods. Expanding the reach of health systems to rural areas and better utilisation of the evidence base(Kok et al., 2014) on maximising the performance of community health volunteers could strengthen the role of this cadre in early case detection for NTDs.

Health personnel described a key health systems weakness as an absence of referral between the NTD programme and mental health clinicians at point of diagnosis. Both NTD and mental health specialists suggested that the introduction of mental health screening and counselling at point of diagnosis accompanied by a strengthening of referral between these departments would strengthen responses to patient support needs. Our analysis concurs with Litt et al. (2012), who see 'mainstreaming mental health support within NTD treatment' as a critical step in meeting the psycho-social support needs of affected populations(Litt et al., 2012). However, key informants identified human resources capacity gaps at the primary and secondary health care level as likely hinderances to cross-departmental collaboration and referral. By taking a syndemic approach to care at the community level, through the provision of integrated (non-disease specific) psycho-social support interventions, these capacity gaps have been addressed in other sub-Saharan African settings. For example, 'community friendship benches'(Chibanda et al., 2016) that train lay community workers to deliver counselling services have been shown to alleviate symptoms of depression(Chibanda et al., 2016) in Zimbabwe. Capitalising on these approaches

could support in fostering a more holistic response to the health needs of persons affected by NTDs in Liberia.

7.6 Conclusion

Syndemic relationships have been most clearly articulated in relation to HIV(Mendenhall et al., 2017). However, advancing syndemic theory and responding effectively to the health needs of populations within LMICs, requires application of syndemic theory to other disease conditions(Mendenhall et al., 2017). Our findings suggest that there is a specific need for further exploration of the syndemic relationship between NTDs and mental distress in the context of structural violence (post-conflict fragility, poverty, gendered social norms, stigma, and weak health systems infrastructure). We have argued that ongoing social inequalities and the broader political economy in Liberia, create a perpetuating cycle of negative health and social outcomes for those affected by mental distress and NTDs that will require multi-level systems responses. Intersectional theory has allowed us to consider how structural violence becomes embodied in different ways through interacting multi-level processes that shape experience according to social location. Thus, intervening to transform the social, environmental or political factors that contribute toward the interactions between health conditions is essential in minimising burdens of ill-health associated with NTDs and mental distress (Mendenhall et al., 2017).

The utilisation of an unstructured methodology in the form of narrative case studies, allowed affected persons and their families to guide the narrative direction and prioritise what was important in sharing their reality. Unstructured qualitative methodologies such as these can be useful in advancing syndemic theory and in exploring syndemic interaction in other contexts, as they provide deep understandings of the mechanisms that lead to syndemic relationships(Maher, 2002, Tsai, 2018). The power of experience in guiding our exploration of syndemic suffering was essential to be able to fully understand its complexity; by taking an intersectional approach to analysis we were able to better explore how lived experiences cannot be separated from larger socio-political contexts that shape people's ways of being in the world(Mendenhall, 2016). We propose that it is the critical analysis of

experience that enables the development of appropriate people-centred responses to syndemic suffering, which, in striving to redress existing social and structural inequities is more useful than quantitative analysis in isolation.

Evidence of systems weaknesses, including poor human resource capacities, inadequate diagnostic infrastructure and absent referral pathways, present a need for the development of high-quality integrated approaches for the management of NTDs in Liberia(Engelman et al., 2016, Hay, 2016, Mitjà et al., 2017). However, 'integration' within health systems discourse has predominantly focused on merging and co-ordinating disease control activities within health-care delivery(Gyapong et al., 2010), with limited consideration of the biosocial interaction of disease. Our study presents a critical need to bring together health systems and syndemic discourses to broaden the focus of integration to consider 'syndemic care'(Mendenhall et al., 2017, Mendenhall et al., 2015). Syndemic care approaches within health systems development would not only maximise resource use but allow for the consideration of the biosocial context of disease and the development of interventions to transform this.

7.7 Research highlights

- NTDs and mental distress have a syndemic relationship catalysed by stigma
- The context of structural violence in Liberia is key in shaping disease interaction
- Together intersectional and syndemic theory show how structural violence is embodied
- Narrative methods allow syndemics to be explored from the view of the marginalised
- Syndemic care is essential in designing people-centred health systems in LMICs

7.8 Acknowledgements

We would like to thank all the participants who took the time to engage with us to be a part of this study and shared honest and challenging accounts of highly personal experiences. We would also like to extend our gratitude to the Government of Liberia, Ministry of Health, National NTD programme and the County Health Teams of Nimba, Bong and Maryland who facilitated district and community access and provided ongoing logistical support.

7.9 Ethics Statement

Ethical approval was obtained from Liverpool School of Tropical Medicine (16.070) and by the University of Liberia, Pacific Institute for Research and Evaluation Institutional Review Board (17-02-024).

Chapter 8: Discussion

8.1 Chapter Overview

Within this chapter I present a summary of the main findings and how chapters five to seven come together to support in addressing the main aim of this thesis; to support the development of equitable and effective people-centred health systems responses to Neglected Tropical Diseases in Liberia. I draw together the in-depth exploration of the context of chronic morbidity and disability as a result of NTDs in Liberia and link to wider theoretical concepts and literature to advance the knowledge base in shaping health systems responses in Liberia and beyond. I make recommendations for future research or intervention and discuss the strengths and limitations of the work. Recommendations are structured around WHO's five interdependent strategic directions to support in shaping the development of integrated people-centred health systems(World Health Organisation, 2015). These strategic directions are used as an alternative to Sheikh et al. (2014b) core principles outlined in chapter five, as they represent practical and strategic areas for action, as opposed to enabling reflection on the overarching values and vision for health systems reform. Table 9 presents a summary of the interlinkages between this thesis' main finding threads, as well as the methods and analytical approaches from which the key findings were derived. Table 9 also presents the interlinkages between findings and recommendations that are presented within section 8.3.

Table 9: Overview of thesis findings and their interconnections with methods, analytical approaches and recommendations

Key Findings ***(NB: the section of the thesis where further detail is provided is given in brackets)***	**Derived From (Method and Analytical Approach)**	**Recommendations (Informed by findings and literature)** ***(NB: the section of the thesis where further detail is provided is given in brackets where it falls outside of Chapter 8)***
Empowering and Engaging People: Creating a social collective of people affected by NTDs and supporting community-based rehabilitation (CBR) through community-based intervention(s)		
As a result of social and structural inequities, people affected by NTDs face multiple **participation restrictions** (see section 6.7), including: • In **decisions to seek care**- authority of health care providers (clinicians and country doctors), age and gender shaped individuals' power in care seeking (6.7.1.1) • Being **unable to attend school-** leading to feelings of loss and social isolation (6.7.2.1) • Being **unable to fulfil gendered ideals**- men feeling unable to fulfil livelihood activities led to challenged masculinities; for women transition to 'dependent' and inability to care for household led to feelings of worry and anxiety (6.7.2.1; 7.5.2.1.2)	Illness Narrative Case Studies Narrative and Intersectional Analysis Syndemic Analysis (utilisation of minority stress model-7.5.2)	**Patient Advocates** to support in identification of affected persons and in care delivery (Davey and Burridge, 2009). **Community Awareness Campaigns** to promote stigma reduction (Hofstraat and van Brakel, 2016; Tora et al., 2018)

Stigma (enacted, hereditary, internalised/anticipated) is a key structural mechanism of the syndemic relationship between NTDs and mental distress in the context of structural violence in Liberia (7.5) Stigma also leads to **social Isolation** (6.7.2.2; 6.7.3.1; 7.5.2.1.2; 7.5.3)		**Community-based participatory learning programmes** are required to redress social inequities and to create and enabling environment for people affected by NTDs. This is particularly critical in minimising the contribution of power hierarchies in shaping negative disease interactions (e.g. between NTDs and mental distress). Stepping Stones, is one example of this.
Key Coping Mechanisms Included: • Reliance on religion and faith in navigating trauma, rationalising experience and practicing forgiveness (6.7.3.2). • Identification of safe spaces (e.g. settling around leprosy treatment centres) or individuals in the community to seek guidance and support (6.7.3.3). • Interactions with other people affected to support in processing illness experience (6.7.3.3).	Illness Narrative Case Studies Narrative and Intersectional Analysis	**Peer Support Groups** to support with medical management e.g. washing and wound management (Tora et al., 2018), but also to improve self-respect and community participation (Benbow and Tamiru, 2001) (6.8.3.1). Support groups that span chronic disease conditions should be considered.
Strengthening Governance and Accountability: Promoting good governance and systems integration by: capitalising opportunities for change; prioritising the creation of equitable partnerships between actors at all levels of the health system including affected persons; and aligning to broader health systems interests.		
The political history of Liberia has created aid dependency that: • limits autonomy in decision making for of the NTD programme • reduces the responsiveness of the programme to national priorities.	Key Informant Interviews Reflexive Diary	Utilise the post-crisis period to consider innovation and **new forms of collaboration** (Martineau, 2016). Consider: • Harmonisation and alignment of vertical disease programme to broader health systems priorities and strategies to support the navigation of deep routed

The Ebola epidemic created a **'window of opportunity'** for policy and programme reform, particularly as integration goals aligned to broader health systems policies (5.5.1.1; 5.6).		imbalances of power within existing political and donor infrastructure.
Participation deficit of civil society including people affected by NTDs in policy and programme reform and decision-making has led to a current absence of participatory governance (5.5.1.2; 5.6).	Key Informant Interviews Reflexive Diary	Further **implementation research** is required to understand best practices of **participatory governance** in Liberia (5.6). Establishing mechanisms for promoting external social accountability of service providers to communities is essential. **Peer-Support Groups** could facilitate participatory action and collective governance (6.8.3.1).
Re-orientating Model of Care: embodying a holistic understanding of health by prioritising primary and community level intervention and co-ordination of services between health systems levels.		
Health Seeking Delays are exacerbating morbidity, disability and associated stigma as a result of structural inequities including (7.5.2.1.3): • **Poor Quality of Care**: Lack of skilled health workforce available for diagnosis or mis-diagnosis (6.7.1.2); stigma experienced by affected people from health workers (7.5.2.1.3) • Weak supply chains leading to a **shortage of medicines** and inability to meet increased demand (5.5.2) • **Limited absorptive capacity** of the health system due to limited human	Key Informant Interviews Reflexive Diary Illness Narrative Case Studies Narrative Analysis Intersectional Analysis Syndemic Analysis (consideration of how health and social systems contribute to responses- 7.5.3)	**Active Case Searching:** • Consider the use of community health cadres whilst also maximising use of evidence on managing performance (Corley et al., 2016; Kok et al., 2014; Raven et al., 2015) with a specific focus on implications for equity (5.6) (Starfield, 2011). • Align activities to ongoing community health systems reform in Liberia. • Patient Advocates to support case finding (Davey and Burridge, 2009). **Improve Diagnostic Pathways and Processes** by: • Piloting application of easy to use clinical diagnostic tools with primary health care

resources and minimal focus on systems strengthening (5.6) • **Limited understanding of disease severity** (6.7.1.1) • **Pluralistic belief systems** led to a web of complex care seeking (6.7.1.1; 7.5.3) • **Conflict** (7.5.2.1.3) • **Financial Barriers** (7.5.2.1.3) Earlier case detection by community health assistants working well due to integrated training, supervision, and motivation aligned to MoH community health division policy. Enhanced by provision of active case search incentive policy (5.5.2).		workers e.g. WHO algorithm for stigmatising skin disease; SkinApp (World Health Organisation, 2018) • Implementation research designed to strengthen laboratory system and supply chain for rapid tests and microscopy as well as PCR testing. **Improve co-ordination and collaboration with pluralistic service providers**. Participatory dialogues could be facilitated to enable this collaboration (see section 8.3.4).
Co-ordinating Services: Ensuring a continuum of care and considering the complex interplay between physical disability, mental illness and associated stigma.		
NTDs can lead to 'biographical disruptions' or 'narrative wreckage' causing individuals to oscillate through periods of chaos, quest and restitution within their illness narratives. The extent of disruption is negotiated and mediated within different spaces and places based on intersecting social strata. Diagnostic communication, acknowledgement of plurality in health seeking, and triggers for periods of chaos are essential in holistic management of NTDs (6.7; 6.8.2).	Illness Narrative Case Studies Narrative analysis using Frank's (1995) narrative types Intersectional Analysis Syndemic Analysis	Respond to oscillation within chronic illness trajectories through the provision of **holistic and long-term care which involves moving beyond curative disease models** (6.8.3.1). This means addressing social and economic support needs as well as the provision of medical intervention as discussed in the following rows.

Ongoing social inequalities and the broader political economy in Liberia create a perpetuating cycle of negative health and social outcomes for those affected by NTDs and mental distress that will require multi-level systems responses (Chapter 7).		Application of syndemic theory to other chronic disease conditions could be beneficial in mainstreaming disability within health systems reform (7.6).
Loss of hope of positive prognosis, debilitating attacks, disease flare ups and periods of intense pain created return to periods of chaos and associated psychological distress (6.7).	Illness Narrative Case Studies Narrative analysis using Frank's (1995) narrative types	**Patient advocates** to promote self-care to reduce the impact and frequency of acute attacks (Tora et al., 2018) **Peer-support groups** that prioritise the management of chronic pain. **Early case detection** through active case finding to limit risk of reduced positive prognosis (6.8.2) **Provision of specialised rehabilitation or habilitation services** including the provision of assistive devices. Use of ICF as a tool to design rehabilitation programmes to explore the interactions of functional limitation and environment leading to participation barriers (Madden and Bundy, 2019).
Post-conflict environment leads to generalised stressors (pain, poverty, precarious livelihoods, financial stress) that intersect with gendered identities to shape experience, impact and meaning of illness, chronic morbidity and disability. Specifically, when catalysed by stigma	Illness narrative case studies Syndemic Analysis (utilisation of minority stress model-7.5.2)	Consider applicability of socio-economic rehabilitation to contribute toward stigma reduction through the provision of: • skills training • enhancing entrepreneurship • educational opportunities

can lead to periods of psycho-social distress (7.5.2.1).		
Co-occurrence of epidemics of NTDs and mental distress in Liberia (7.5.1). Feelings of helplessness worry and anxiety leading to suicidal thoughts and or attempts (6.7; 7.5.2). Religion and faith support individuals through periods of psychological distress linked to a renewed sense of purpose or belonging within the community (6.7).	Illness Narrative Case Studies Narrative Analysis Syndemic Analysis (utilisation of minority stress model-7.5.2)	Enhance co-ordination and collaboration between health and social care professionals focused on mental ill-health and chronic conditions at co-ordination levels within the health system (national and county). For example, through establishing integrated case management teams (6.8.3.2). Explore strategies for decentralisation of mental health service provision, for example through the use of: • Friendship benches (Chibanda et al., 2011) • Community-based participatory learning dialogues (see above) Strengthen referral pathways at primary and secondary treatment level to MhGAP trained clinicians who are able to provide 'talk therapies' to affected persons.
Programme implementers often found addressing all support needs of affected persons at once 'too big'. This led to some feeling compromised in being able to deliver a fully integrated programme and in some cases caused personal distress (5.5.1.2).	Key Informant Interviews Reflexive Diaries	Mental health support to health workers and community members caring for affected persons should also be provided.

Creating an Enabling Environment: Ensuring that transformational change continues by navigating power dynamics and recognising health systems as inherently political.		
Long term reliance on donor funding limits programme flexibility even within integrated approach. Ongoing prioritisation of disease specific funding from some donors within limited space for two-way feedback mechanisms (5.5.3). Values and social relationships shape	Key Informant Interviews Reflexive Diary	Focus on capacity strengthening to ensure a clear role and function of national actors in health governance, priority setting, and adaption of international agendas to local context to strengthen bureaucratic accountability (5.6.1). Encourage flexible funding flows to allow leadership and innovation by national actors (5.6). Develop a strong evidence base that supports the value of the innovative integrated approach to managing NTDs in Liberia.
Values and social relationships shape decision making within health systems (5.6; 6.8). Narratives are a useful tool in documenting the needs and values of affected persons and have a unique emotive power that has the potential to have sustained impact on decision makers that can guide future action. Creation of the 'meta-narratives' can allow temporal 'commonalities' in experiences to be documented to support in the generation of chronic care packages that are responsive to need and guided by lived realities (6.8).	Key Informant Interviews Reflexive Diary	Further research that explores the use of narrative within social accountability processes. They should be capitalised in supporting evidence informed decision making amongst policy makers and programme implementers to move away from paternalistic approaches to health and healthcare.

Strong inter-personal relationships between actors at various levels of the health system due to supportive supervision processes (5.6).		

8.2 Main Findings in Context

Within chapters one and two of this thesis, I explained that this work departs from traditional biomedical approaches to health that historically dominate NTD discourse (Parker et al., 2016), to consider how the social context within which these diseases are located shapes illness experience. From this deep exploration of illness experience, which I situate within the broader political economy of Liberia, I am able to make recommendations about how the NTD community and health systems actors could act to change the way services are delivered to ensure they are responsive to individual needs and values and thus more person-centred (see section 7.3). This is described as a long-term goal of NTD programmes on the path to 2030, and seen as an essential step within current movements toward UHC, which place intensified pressure on vertical disease programmes (e.g. PCT NTD programmes) to take steps toward operational integration within generalised health systems(Fitzpatrick and Engels, 2016, Smith and Taylor, 2016).

Chapter five considers the extent to which the current policy and programme context in Liberia supports a focus on the development of integrated, people-centred health systems. By considering the alignment of core principles and values between ongoing NTD programme reform and the development of people-centred health systems, I was able to illuminate multiple push and pull factors that help or hinder the establishment of a continuum of care for affected persons (see Figure 8). For example, as has been articulated by others (Nabyonga-Orem et al., 2016), the political history of Liberia has created crippling levels of donor dependency, that undoubtably limit the responsiveness of the health system to national priorities. However, the strength and determination of the NTD team to challenge the pull of vertical approaches and push for integrated systems reform is clear. Thus, in supporting the drive toward UHC, through the development of integrated DMDI interventions, the NTD community should capitalise 'windows of opportunity' within varying and diverse contexts, and align their interests to broader health systems priorities and strategies that can enable navigation of deep routed imbalances of power within existing political and donor infrastructure. This is also relevant to

continuing to maintain an enabling environment for systems reform- described in section 7.3.5.

Narratives are the central method drawn upon (chapter three) and have functioned as windows into the lives of individuals living with chronic illness (Mendenhall, 2016). Narratives within this thesis should be seen as evolving as people's lives are still ongoing, life stories remain unfinished (Whitehead, 2006). Narrative analysis has enabled the consideration of how individual suffering linked to NTDs is shaped and mediated by social and cultural context (Kleinman, 1980) and, as has been described by others (Christensen and Jensen, 2012), has proved to be a useful tool in applying intersectional theory as fluidity of experience can be analysed.

Through the application of narrative analysis that draws on Frank's narrative types, Chapter five describes how NTDs create a profound disruption in people's lives that leads to periods of restitution, chaos and quest within narrative accounts. To my knowledge, this is one of the only studies focused in LMICs that draws on Frank's narrative types in analysis. By merging this form of narrative analysis with intersectional theory, I was able to consider how unique and interconnected social and structural processes, that shape individual identity, intersect to shape illness experiences. Exploration of how individual positionalities inform complex health seeking pathways, in the contexts of multiple understandings of disease aetiologies and medical syncretism, allowed for the development of a 'meta-narrative' that supports in making recommendations for policy design and programming (see section 8.3) through analysis of collective yet individualised experiences.

The successful application of the use of narrative methods, and analysis that engaged with Frank's narrative types and intersectional theory, presents an important learning for the global health community. Changes in patterns of illness in many LMICs, have shown a rise in the incidence of chronic conditions as well as a rising burden of non-communicable disease (Mendenhall et al., 2017). People-centred health systems must be able to respond to these new and emergent challenges and the analysis I present within this thesis highlight the potential value of narrative analysis in guiding adaptive processes. Management and social support for people affected by chronic conditions and associated disability, requires long-term holistic

approaches, as revision of self-narratives become central to illness or life experiences (Mendenhall, 2016). However, re-orientating health systems to be able to manage such epidemiological transitions is challenging, based on the historical dominance of bio-medicine in systems design, which can limit the responsiveness of systems to care needs that demand anything more than acute responses(Marchal et al., 2011, Mounier-Jack et al., 2017). Experiences of narrative use within this thesis present two opportunities for health policy and systems researchers from, and working within LMICs: 1) narratives have been shown here and elsewhere (Fadlallah et al., 2019) to be a powerful tool in documenting the experiences, needs and values of affected persons, and should be capitalised in supporting evidence informed decision making amongst policy makers and programme implementers to move away from paternalistic approaches to health and healthcare; and 2) the creation of the 'meta-narrative' can allow temporal 'commonalities' in experiences to be documented to support in the generation of chronic care packages that are responsive to need and guided by lived realities (Pluta et al., 2015).

Vulnerabilities exist in multiple forms, of which being affected by an NTD may be one. However, as is reflected in the narratives drawn upon throughout this thesis, illness experience often relates to a collection of challenges that *'produce, exacerbate and maintain chronic and seemingly insurmountable disadvantage'* (Singer et al., 2017bp142). Thus, simply focusing on stories and policy and programme reform without considering the broader social and structural factors that shape why health inequities exist would have limited my analysis. Chapter seven draws findings and understandings from chapters five and six together, through the application of syndemic theory to consider the biosocial relationship between NTDs, chronic morbidity, disability and mental distress in Liberia.

Few studies have considered how the complex dynamics of structural violence have shaped epidemiological transitions in low- and middle- income countries (LMICs)(Mendenhall, 2014). Additionally, research on how specific historical trajectories shape both population and individual experiences of the increased incidence of chronic conditions is particularly limited (Mendenhall, 2014). Thus, by infusing syndemic thinking with concepts of structural violence and intersectionality,

I was able to advance theoretical thinking in relation to chronic disease and disability in LMICs, by illuminating how social and structural inequities as a result of conflict and fragility become embodied in varying ways to shape health and disability. Considering responses to syndemic suffering through the development of people-centred health systems that prioritise 'syndemic care' (see section 8.3) aligns to capability approaches to disability, by situating negative health conditions within the broader resource, physical and social environment within which they are located (Mitra, 2006a). Application of syndemic theory to other chronic disease conditions could therefore be beneficial in mainstreaming disability within health systems reform.

In Chapter seven, I argue that: 1) the post-conflict environment in Liberia predisposes people to the chronic effects of NTDs as well as other 'generalised stressors' as a consequence of ongoing structural violence; 2) people affected by NTDs are additionally exposed to stigma and discrimination that cause additional stressors and synergistically produce negative health outcomes in relation to NTDs and mental distress; and 3) the impact and experience of consequential syndemic suffering is shaped by intersecting axes of inequity such as gender and generation which are themselves created by unequal power distribution across multiple systems levels.

Stigmatising and gendered experiences as a result of underlying power relations have been identified in relation to other chronic diseases such as HIV and TB (Jewkes et al., 2008, Paine et al., 2002, Zvonareva et al., 2019). As is the case here, these experiences frequently lead to periods of social isolation and mental distress and require approaches that are transformative and contribute toward redressing existing power hierarchies (discussed more in section 8.3.1). Based on the analysis presented within this thesis, syndemic models infused with theories of structural violence and intersectionality should be considered within other LMIC settings as a core mechanism through which interlinkages between chronic illness, mental distress and associated negative health outcomes such as violence can be identified. This could support in addressing the embodiment of negative structural and social inequities amongst marginalised individuals and contribute toward enhancing health and wellbeing amongst vulnerable populations.

8.3 Implications for Health Systems and Future Work

WHO present five interdependent strategic directions that can support in shaping the development of integrated people centred health systems (World Health Organisation, 2015). These strategic directions are designed to generate a set of actions that can support in transforming health systems to enable service delivery that is both integrated and people centred. Each strategic area is summarised in Box 8. Within the subsequent section, I consider each of these strategic areas in relation to the findings and recommendations presented across chapters five to seven, as well as eliciting further areas for action based on combined analysis and reflections. Each of the actions or recommendations are framed to support the transition of the Liberian NTD programme toward more people-centred DMDI service delivery to support the management of chronic morbidity and disability associated with NTDs. However, health systems reform is complex and requires sustained political will and commitment (World Health Organisation, 2015). The recommendations presented within this sub-section are not intended to be an exhaustive list that considers all health systems components. Rather, they are presented to enable a step in the right

direction toward 2030 that is guided by the needs and values of affected persons (see section 1.2.1).

8.3.1 Empowering and Engaging People: recognise people as assets and building social networks

Throughout this thesis, people and communities have been recognised as assets in the co-production of health and social care priorities, in an attempt to engage those who are frequently the most marginalised in developing recommendations that can

Box 8: Strategic Directions for Supporting the Development of Integrated People Centred Health Services (World Health Organisation 2015)

Empowering and Engaging People: Provide individuals and communities the opportunity, skills and resources they need to be able to make effective decisions about their own health, ultimately becoming co-producers of health services and healthy environments. Focus specifically on minorities or those with the greatest health needs.

Strengthening Governance and Accountability: Promoting transparency in decision making and collective transparency of health providers and health systems managers through aligning governance and accountability incentives.

Re-orientating the Model of Care: Efficient and effective care is purchased and provided through models of care that prioritise primary and community care services and co-production of health. Focus on holistic care delivery and a shift to outpatient care and efficient and effective referral systems. Intersectoral collaboration at the community level becomes critical in shaping how social determinants of health are addressed.

Co-ordinating Services: care should be co-ordinated around the needs of people at every level as well as including other sectors in an attempt to overcome the fragmentation of care delivery.

Creating an Enabling Environment: Need to bring together different stakeholders to enable transformational change.

support the design and planning of health services (World Health Organisation, 2015). Strategic priority 2, within Liberia's 'Strategic Plan for Integrated Case Management of Neglected Tropical Diseases', advocates for increased community awareness and engagement in NTDs requiring case management, as a means of supporting resource mobilisation and involvement in planning (see Box 1). However, many people affected by NTDs, including family or household members, whose narratives are shared within this thesis, face multiple participation restrictions (see section 6.7) that limit their abilities to engage with the health system or demand

social change. Creating a social collective of people affected by NTDs, through varying community interventions, has been shown to be effective in empowering individuals and families, who are affected by NTDs and other chronic conditions(Acha et al., 2007, Tora et al., 2018), to take control of their own health and wellbeing as a result of stigma reduction and increased social participation. Exploring adaptation of best practices in relation to community interventions for people affected by NTDs in Liberia could support in empowering and engaging people affected to come together to demand social and systems change. Examples of community-based interventions that could be considered for adaptation through implementation research are described as follows:

Patient Advocates: In southern Ethiopia, persons affected by lymphoedema as a result of podoconosis, have been shown to be a useful resource in identifying other affected persons and in supporting them with self-care. Affected persons, who are educated to high school level, receive one week of clinical training prior to beginning case searching and providing support to affected persons (Davey and Burridge, 2009). This is a particularly useful strategy in contexts where access to formal health services is limited, and patient location is disparate, as is the case in Liberia, and could be a powerful solution in improving social support(Tora et al., 2018). Supporting enhanced management through self-care, also contributes to reducing experiences of temporal morbidity in relation to lymphoedema as a result of acute attacks(Tora et al., 2018), and as such can increase social participation of affected persons by reducing negative impacts to economic productivity and household activities.

Peer-support groups: have been shown to be a useful tool in enabling individuals to self-manage illness, particularly for chronic conditions such as lymphoedema and leprosy that require routine washing and wound management (Tora et al., 2018). Although many peer-support groups are frequently established to manage the medical needs or complications of illness, studies have also shown that such interventions have led to increased self-respect and community participation amongst group members (Benbow and Tamiru, 2001). Similarities in illness experience irrespective of 'disease condition' described within narratives of affected persons in this thesis, suggest that peer-support groups that include individuals

affected by multiple chronic conditions are worth consideration in Liberia. This supports findings from a systematic review in 2016, that highlighted that integrated approaches to disease management and stigma reduction should be considered for NTDs due to similarities in causes and manifestations of multiple conditions (Hofstraat and van Brakel, 2016). Delivery of strategies for the management of chronic pain could also be explored within peer-support groups as painful somatic experience was commonly emphasised within narratives of affected persons (see chapter five and six). Finally, in counties and communities in Liberia where disabled persons organisations exist, they could also be leveraged to support the design, delivery and monitoring of peer support groups as well as health policy generation.

Community-Based Awareness Campaigns: Raising awareness amongst communities about the causes, treatment and prevention of NTDs is critical in supporting to reduce stigma of affected persons. Awareness or education campaigns must be responsive to local needs and understandings in relation to health and illness, and could focus on household skill building activities that enable individuals to think critically about their place in the wider community. Such approaches can enable reduction in the attitudes and prejudices held by community members about people affected by NTDs, and also improve the perceptions of people affected about their own capabilities, thus reducing both felt and enacted stigma (Hofstraat and van Brakel, 2016, Tora et al., 2018).

Gender Transformative Approaches: Tackling the complex social and structural causes of morbidity and disability associated with NTDs also requires intervention approaches that address engrained power imbalances. As described in section 6.5.3 'Stepping Stones' is one example of a gender transformative community-based participatory learning programme that could be adapted to create a more inclusive environment for people affected by NTDs. By focusing on community norms and values, such approaches are in line with people-centred responses to ill-health as they are adaptive to the contextualised experience of suffering at the community, household and individual level. Participatory processes of adaptation and learning

similar to 'Stepping Stones'[15] could support in the design and delivery of 'syndemic care'(Mendenhall et al., 2017) in relation to NTDs and mental distress in Liberia.

The approaches described above align to community-based rehabilitation (CBR) practices which are commonly utilised to support people with disabilities. CBR has undergone a rapid period of evolution from a predominantly medicalised approach to one that puts holistic needs first whilst keeping people with disability in their communities, to enhance opportunities for participation and inclusion. Thus, CBR approaches have the potential to inform the implementation of people-centred chronic care strategies that prioritise support for families and affected persons at the micro-level(Allotey et al., 2010). Three key learnings that have made CBR successful are: prioritising participation at community level; developing strong partnerships within and across sectors (see section 8.3.4); and eliciting government support to facilitate and fund the CBR process (see section 8.3.5). Harnessing support from other affected persons and capitalising the power of local communities is clearly essential in advocating for the rights of people affected by chronic morbidity and disability as a result of NTDs in Liberia. Patient advocates and support groups could also serve as a useful resource for the NTD programme and health system in Liberia as they move toward the development of a more person-centred health system; such groups and individuals could be engaged to provide feedback on national and sub-national policies and plans aimed at responding to their health and wellbeing needs and priorities.

8.3.2 Strengthening Governance and Accountability

Good governance within the design and delivery of people centred health systems is that which allows for the consideration of the roles and relations of all systems actors, whilst ensuring that all voices are heard and consensus is achieved (Abimbola et al., 2014, World Health Organisation, 2015). By integrating service delivery, people-centred health systems seek to bring together disparate strategies and priorities of varying donor agencies and vertical programmes with the view that

[15] Stepping stones is a participatory training package on HIV/AIDS, gender, communication, and relationship skills designed for use with affected communities to support in addressing stigma, discrimination and gender-based violence.

tackling specific diseases should not override overall systems priorities (World Health Organisation, 2015). Martineau (2016), describes that the post-crisis period frequently presents health systems with an opportunity for innovation and collaboration that is not confined within existing parameters of implementation. He suggests that it is during these times, that the most novel of approaches can be realised to accelerate development and provide learning for other settings (Martineau, 2016). Chapter five describes in detail how this was the case in regard to the development of the 'Strategic Plan for Integrated Case Management' in Liberia. A space was created that supported programme implementers to challenge deep rooted 'chronic verticalization' in NTD programme delivery (Gonzales et al., 2019), and push toward integrated, people-centred responses. Harmonisation and alignment of vertical disease programme priorities with broader health system policies, strategies and plans, further supported to shift the power balance toward enhanced country ownership. However, as also described in chapter five, country ownership is still frequently restricted due to donor restrictions, which are reinforced and mediated by programme implementing partners, and promote disease siloed funding.

As reflected in the Accra Agenda for Action (OECD, 2008), strengthening of governance and bureaucratic or horizontal accountability mechanisms(Abimbola et al., 2014, TAI, 2017) to promote country ownership, and establish more equitable and effective inclusive partnerships with donors, is essential to enable continued innovation within the NTD programme in Liberia that can support the strive toward the delivery of people centred services.

The creation of equitable partnerships and democratic checks and balances between government actors, civil society organisations, and community members is also essential in ensuring strong governance and accountability processes. As further described in chapter five, a current participation deficit of civil society, including people affected by NTDs, in current decision-making processes limits external social accountability of the health system (Abimbola et al., 2014). Further implementation research that applies existing evidence to explore which mechanisms for enhancing the external social accountability of service providers to communities are most

appropriate in this context is critical, so that people affected by chronic illness and their communities are empowered to take-action and demand quality services. The feasibility of decentralising decision making to district and community level, for example, through existing community platforms such as village health committees, could be considered as an initial first step in supporting the development of external social accountability processes. Capitalising on community level interventions as described in section 8.3.1 could also help in this regard. Learning from other sub-Saharan settings would also suggest that an initial step in establishing external social accountability processes could be to ensure adequate information and training is available to community members to be able to make assessment of the service provided (Tora et al., 2018).

8.3.3 Re-orientating the Model of Care

Person-centred systems require a re-orientation of care models to embody a more holistic understanding of health whilst prioritising primary and community level intervention (World Health Organisation, 2015). This is not to completely substitute other levels of care, rather effective co-ordination of services between levels should be established (World Health Organisation, 2015). Simultaneously, models of care for chronic conditions echo the need for holistic understandings of health that are different from disease orientated approaches by prioritising: a focus on disability limitation and rehabilitation; attention to the psychosocial aspects of the affected person (see section 8.3.4); involving and enabling the affected person in managing the condition (see section 8.3.1); case finding for the assessment of risk factors, detection of early disease and identification of risk status; and long-term follow-up with regular monitoring, and promotion of adherence to pharmacological and psychological interventions (see this section, 8.3.1 and 8.3.4) (Ku and Kegels, 2015). In the subsequent few paragraphs, I describe recommendations for specific systems strengthening activities or future research that could support in the delivery of person-centred care for chronic NTDs in Liberia, thus contributing to the attainment of Strategic Priorities 3 and 4 (see Box 1) within Liberia's 'Strategic Plan for Integrated Case Management' (Ministry of Health, 2016). Specifically, I consider how taking a systems approach to addressing health system weaknesses in the detection,

diagnosis and treatment of many NTDs in Liberia can contribute to reducing associated suffering as a result of exacerbated morbidity and disability.

Active case searching should be a central priority in promoting the early identification and treatment of disease, whilst simultaneously bringing service delivery closer to communities. Such approaches are essential to reducing barriers to health service access and limited self-reporting due to fear of stigmatisation and social isolation. However, ongoing human resource shortages in Liberia, as is experienced elsewhere in sub-Saharan Africa(Gile et al., 2018), are likely to limit the ability of the NTD programme and health system to be able to complete such activities without engagement of community health cadres. Utilising community health cadres to actively identify and refer cases has shown promising results with respect to Buruli Ulcer in Cameroon(Corley et al., 2016), however better utilisation of the extensive evidence on maximising the performance of CHWs(Kok et al., 2014, Raven et al., 2015) could strengthen the role of community health cadres in the completion of such activities, and is crucial to effectiveness of integration. Future research that uses a human resource management approach(Armstrong and Taylor, 2014) could enable analysis of what could help or hinder the resourcing and support for active case searching and referral at community level, and to ensure the alignment of these activities to ongoing community health policy reform in Liberia. Consideration of the other roles that community health cadres are expected to perform and who defines these tasks or priorities should also be considered in the context of holistic planning of community health cadre roles. The needs, priorities and rights of community health cadres should be at the forefront of this decision making. As described in section 8.3.1, patient advocates could also be used in active case detection strategies.

Once detected and referred, the ability of the health system to provide accurate and timely diagnosis is also essential to minimise experience of mis-diagnosis, treatment delays and consequential periods of biographical turmoil (see chapter six). However, existing health system capacity to provide reliable clinical diagnosis and confirmatory testing (where necessary) is currently weak. As is common across multiple settings in sub-Saharan Africa (Yotsu, 2018), clinical manifestations of disease were often

described as misdiagnosed and or ill-managed due to lack of skilled health workers available for diagnosis (Williams and Kovarik, 2018). Consequently, to contribute toward enhancing clinical diagnosis and management processes for these disease conditions, WHO and some international NGDOs have begun to develop easy to use guidelines for health workers to be able to better identify, refer and treat people affected. Examples of such tools and guidelines include the WHO algorithm for stigmatising skin diseases (World Health Organization, 2018), and the integrated SkinApp, recently designed by Netherlands Leprosy Relief (NLR). Working with health systems stakeholders to adapt, test and implement such tools within the Liberian context, could support in reducing the burden of chronic morbidity and disability associated with NTDs in Liberia by promoting earlier diagnosis and treatment.

As described by key informants (see Chapter five), for diseases reliant on confirmatory testing using PCR or other specific tests, such as Buruli Ulcer, laboratory systems are frequently under-skilled and under-resourced to provide such a service (Yotsu, 2018). Conducting implementation research focused on Liberia's laboratory and supply chain system would likely support efforts to improve the reliability of laboratory results and strengthen the referral and supply systems nation-wide. This would have benefits across the whole health sector, well beyond conditions prioritised within this thesis. This is because the laboratory techniques used to diagnose these diseases, such as rapid tests and microscopy, and the tests used for higher level confirmation (e.g. PCR), as well as the resources required for their management such as antibiotics and dressings, can be applied to many chronic and acute conditions. Identifying and investing in ways to sustainably strengthen Liberia's laboratory and supply chain systems, whilst promoting local ownership, provides a potential option for investment as early case detection and diagnosis is likely to minimise costs associated with long term care needs.

8.3.4 Co-ordinating Services

Service co-ordination is essential to ensure an effective continuum of care within people-centred health systems. Historic focus on episodic experiences result in omission of consideration of the complexity of people's health problems and can limit opportunities to respond adequately (World Health Organisation, 2015).

Literature presented in chapter three, coupled with narrative accounts and key informant data presented across chapters five to seven, emphasise the need for the development of health and social interventions that take into consideration the complex interplay of physical disability, mental illness and associated stigma. This is likely to require better co-ordination within the health system as well as exploration of potential intersectoral partnerships. Within Liberia's 'Strategic Plan for Integrated Case Management', strategic priority 1 (Box 1) stresses the importance of strengthened co-ordination and partnerships for integrated NTD case management. The recommendations presented within this sub-section could be considered as strategic areas for action as the plan is reviewed and revised in 2020.

Support to re-establish or adapt livelihood activities was a key priority within narrative accounts (see chapter six). Socio-economic rehabilitation through the provision of skills training, enhancing entrepreneurship through revolving funds and loans, and providing educational opportunities, are all strategies that have shown to contribute toward stigma reduction and improved livelihoods for people affected by NTDs (Davey and Burridge, 2009, Tora et al., 2018). Testing the applicability of these approaches in Liberia warrants exploration of partnerships outside of the health sector and would be a key step in responding to the needs of affected persons. Such approaches could contribute significantly to reducing 'generalised stressors' (see chapter seven) experienced by affected persons by improving financial independence, autonomy, employment or educational opportunities, whilst also enhancing social integration (Ebenso et al., 2007, Tora et al., 2018).

Enhancing co-ordination, collaboration and learning between health and social care professionals focused on mental ill-health and those working on chronic health conditions, including NTDs, is paramount based on the narrative accounts within this thesis. Reduction of mental health stigma and provision of psycho-social support has been shown to be most effective when interventions prioritise social contact (Mehta et al., 2015, Thornicroft et al., 2016, Madden and Bundy, 2019). Learning from other LMIC settings, suggests that the decentralisation of mental health services that engage communities is essential to achieving sustained social contact in the provision of longitudinal psycho-social support. However, evidence regarding the best

practices to decentralise services is still emerging (Tora et al., 2018). Community approaches such as 'friendship benches' that train lay community members to identify early signs of depression and anxiety, whilst also providing support to people affected by mental ill-health (Chibanda et al., 2011), are one successful community-based mental health strategy that could be explored in Liberia. Embedding the provision of psycho-social support in community-based intervention strategies described above (section 8.3.1) could also be considered.

Better linkages with ongoing psycho-social support strategies that are currently being implemented within the generalised health system should be explored. For example, strengthening referral pathways to mHgap (World Health Organization, 2016) trained clinicians who are available to provide 'talk therapy' in some primary health care facilities in Liberia, could be a beneficial strategy to support people affected by NTDs who have more complex mental health needs. As has been described by others (Tora et al., 2018), action based learning research that focuses on the best ways to align and integrate the provision of mental health services and those targeting NTDs is necessary and likely to strengthen the capacity of both services. Engagement of persons affected by mental-health conditions, their families and caregivers has also been identified as critical when considering the best approaches to expanding access to integrated primary health care services (Abayneh et al., 2017), and is essential to the development of people-centred responses. Provision of psycho-social support for health workers and community members who provide care to affected persons who are experiencing mental ill-health should also be prioritised.

Specialised rehabilitation or habilitation services are also likely to be necessary for people affected by chronic morbidity and disability as a result of NTDs in Liberia. As well as community-based livelihood and vocational support strategies described above, services that focus on the provision of technology or assistive devices are also likely to be necessary. Madden and Bundy (2019), suggest that the ICF can be a useful tool when establishing new rehabilitation programmes such as these, as it can support increased dialogues between health providers and service users. Affected persons and providers can collaboratively set rehabilitation goals that explore functional limitations, environmental barriers and support the development of a

management or treatment plan that is person-centred. Provision of generalised and specialised health services together in this manner aligns to and would provide further evidence regarding the benefit to twin-track approaches for disability mainstreaming within health systems (see section 3.5.2).

Finally, as others have found in relation to generalised health seeking in Liberia, perceptions of disease origins are also deeply rooted within syncretic belief systems, and the lack of consideration of these factors within existing health systems responses further complicates the care seeking pathway and can lead to health seeking delays (Kruk et al., 2011). Thus, evidence presented within this thesis supports literature from other settings (Yotsu, 2018), that has identified the need for improved linkages with a broader range of pluralistic close-to-community health providers in the detection, treatment and management of NTDs and other chronic health conditions. Thus, moving beyond the provision of biomedical interventions to respond to community and individual interpretations of health and illness is necessary. Participatory dialogue with pluralistic and informal health providers could be a first step in the generation of more joined up approaches.

8.3.5 Creating an Enabling Environment

Ensuring implementation of recommendations described in sections 8.3.1 to 8.3.4 requires the ongoing availability of an enabling environment that supports transformational change (World Health Organisation, 2015). Re-orientating health services becomes a political act that challenges existing interests(World Health Organisation, 2015). Thus, the extent to which political actors outside (both internal to Liberia and external donor agencies and implementing partners) of the Liberian NTD programme prioritise the development of people-centred health services is likely to be a limiting factor in ensuring ongoing adaptation and change. Strategic priority 1 within the 'Strategic Plan for Integrated Case Management', prioritises government ownership of the integrated NTD programme by 2021 that will require increased advocacy and visibility of intervention approaches. Collective action between multiple systems actors including the NTD programme, donors, implementing NGDO partners, community health cadres, affected persons, and researchers, to develop a strong evidence base that supports the value of the

innovative integrated approach to managing NTDs in Liberia should be prioritised. Providing policy makers, future donors and collaborating partners with such an evidence base, that has the needs and values of affected persons and health systems actors at the fore, is likely to support in decision making that continues to create an enabling environment for policy, programme and systems reform.

However, ensuring the simultaneous strengthening of social accountability processes is essential to ensure that evidence is used and acted upon. In addition to more traditional approaches to the strengthening of social accountability mechanisms, such as through the use of community score cards(Edward et al., 2015), narrative has the potential to generate lasting impact and enhance systems responsiveness to community priorities. Within this thesis, narratives have been shown to be a useful tool in documenting the needs and values of affected persons and have a unique emotive power that has the potential to have sustained impact on decision makers that can guide future action. Further research that explores the use of narrative within social accountability processes should be considered, particularly given that the fluidity of narrative methods can enable their use with, and participation of, diverse and often marginalised populations as well as other health system actors.

8.4 Limitations and Final Reflections

> *'Taking a standpoint requires self-consciousness about how the fate and choices in your life have positioned you in the world and with whom you have been positioned'(Frank, 2000p356).*

Throughout this thesis, in the relevant chapters, I have provided consideration of specific methodological limitations and continuously reflected on my position within the research study. Frank (2000) suggests that understandings of stories is as much linked to the experiences of the researcher and the subject as it is to the narrative itself. Throughout this work, I have continuously felt challenged regarding the appropriateness of this research study and my role in its construction and implementation. Was or is it right for a white researcher from the global north, to ask people in situations of extreme adversity in the global south, to recount their reality for the benefit of a PhD study? The extreme fragility and weakness of the

health system in Liberia made me reflect further on this. Some of the narratives shared were extremely difficult to listen to, particularly when participants described ongoing experiences of mental distress, and I often felt helpless in being able to ensure that study participants could access the support that they want and need. This presented many ongoing moral and ethical dilemmas.

The emotional response or pre-exposure to 'empathetic witnessing' (Kleinman, 1980) that these stories evoked has undoubtably shaped the way that the analyses of narrative accounts are presented in this thesis. However, as I am now at the end of my thesis journey, I am able to critically reflect on the extent to which my positionality shaped my interpretations. Repeated visits to study participants to build trust and rapport and seek clarity of understandings, coupled with discussion of narrative accounts with my peers in Liberia, supported me to challenge my assumptions about meanings within narrative and increase the trustworthiness of my analyses. Although I can never claim to fully understand the complexities of life in Liberia, and may have still missed some nuance in my interpretations, the inductive thematic saturation reached across narrative accounts(Saunders et al., 2018), including specific attention granted to deviant accounts, further supports the validity of my interpretations. Finally, I seek some solace in the fact that some participants articulated that they had found some comfort in the sharing of narrative accounts, as it was infrequent that somebody asked them about their lives and engaged with their story. I have also talked where possible to people about the narratives of suffering documented within this study to minimise the internalisation of narrative interactions, which is recommended for researchers working with populations who have suffered so deeply (Mendenhall, 2016). Self-consciousness regarding my relative position of power in relation to many of my study participants, leaves me with a sense of moral obligation to do all that I can to support the Liberian health system to make change to better respond to the lived realities of these individuals.

By drawing on intersectional theory throughout this analysis, we have shown that despite similarities in thematic areas presented, individual illness experience is unique and contextualised. During the development of recommendations, I have tried to be mindful of these individualised experiences by developing suggestions

that address broader structural and social inequities or power imbalances. To support in developing recommendations that are appropriate to programme context, study findings have also been disseminated during county health team meetings, national NTD programme review meetings, at international conferences, and in peer-reviewed publications. However, supporting programme implementers to develop recommendations or solutions that are responsive to nuanced needs within ongoing resource limitations has been challenging. As such, many recommendations may appear more generalised to addressing broader health systems weaknesses, rather than those specifically related to nuanced needs documented within this thesis. Additionally, as yet, findings have not been presented back to people affected by NTDs in Liberia (although at some of the conferences where this work has been presented, affected persons have been present). Future funding has been obtained linked to the findings from this thesis, and it has therefore become imperative that within these programmes of work, as recommendations are taken forward, intervention design further engages affected persons. Capacity strengthening activities around gender, equity and intersectional analysis can also be further explored with programme implementers. In 2020, Liberia's 'Strategic Plan for Integrated Case Management' will also go through revision in preparation for a new implementation period. I will continue to work with the Ministry of Health Neglected Tropical Disease Programme to increase representation of affected persons within these policy dialogues as well as to promote the uptake of recommendations presented here.

Study counties are identified pilot sites for the roll out of the strategic plan for integrated case management. As such, the majority of participants engaged within this study were frequently those who are known to health systems actors, and are likely to have better access to DMDI services than those residing in counties where strategy implementation is currently not funded. Thus, those who are the most marginalised or hidden, and currently with the most limited service access, may not have been reached. Reaching these people and understanding their service needs and values is clearly a priority for future work. However, the similarities in priorities and experiences across the three contextually diverse counties included within this

research, as well as across multiple 'disease conditions', suggests that the needs and challenges presented are theoretically generalisable across similar settings in Liberia, and could also be relevant in considering the lived experience of other chronic disease conditions. Furthermore, the addition of key informant data collection that achieved a-priori thematic saturation(Saunders et al., 2018), coupled with ongoing efforts to immerse myself in the Liberian context, supported development of deeper understandings of the socio-political context across Liberia, not just specific study counties, that enabled situation of these findings within broader social and structural systems.

Across chapters five-seven, I draw on multiple concepts and theoretical framings to situate these findings within the wider academic discourse. Nuanced experiences of suffering across varying contexts within and outside of Liberia are likely. However, I believe that the application and adaptation of multiple theoretical frameworks within this study has supported to create explanatory accounts of illness experience in relation to NTDs, that could be relevant in developing health systems responses in other settings in sub-Saharan Africa, particularly those affected by protracted conflict and ongoing systems fragility. For example, as shown here the application of syndemic theory supports in exploring the biomedical, social and structural processes that synergistically interact to shape health inequities, thus supporting the development of multi-layered responses that are essential in establishing people-centred services.

8.5 Conclusion

In conclusion, I have argued that the enormous disadvantage that illness experience associated with NTDs presents is shaped by broader social and structural factors that cause health inequities. NTDs undoubtably create a profound disruption in the lives of people affected, and lived experiences cannot be separated from larger socio-political contexts that shape people's ways of being in the world. I have shown that ongoing social inequalities and the broader political economy in Liberia, create a perpetuating cycle of negative health and social outcomes for those affected by mental distress and NTDs that will require multi-level systems

responses. Thus, addressing NTDs from a biosocial perspective becomes not only an ethical imperative but a matter of social distributive justice. My findings suggest that intervening to transform the social, environmental and political factors that contribute toward the interactions between health conditions is essential in minimising burdens of ill-health, and is critical to ensure that people permanently affected by NTDs are not 'left behind' on the journey to 2030.

People-centred health systems must be able to respond to the rising incidence of chronic health conditions and the rising burden of non-communicable disease. To date, few studies have taken a holistic intersectional approach to inequities and explored their relationship to differing stigmas associated with chronic disease and disability. The analysis I have presented within this thesis highlights the potential value of narrative and intersectional analysis in guiding context specific adaptive processes within health systems that are dynamic and intrinsically linked to broader spatial and temporal factors. Intersectional theory has enabled me to consider how structural violence becomes embodied in different ways through interacting multi-level processes that shape experience according to social location. This has helped me to illustrate that intersectional analysis is particularly important when thinking about the design of holistic interventions that are responsive to the needs of all. By using narrative methods, I have also been able to ensure that the needs, values and realities of the most marginalised are prioritised within this thesis, and it is the critical analysis of experience that has enabled me to develop appropriate recommendations for people-centred responses to suffering.

Justice and a focus on people- not diseases – are key reasons sighted for the increased prioritisation of DMDI within the 2030 NTD roadmap. I have observed that care for people affected by NTDs is the driving force behind the Liberian NTD programme team's determination to deliver integrated, person-centred DMDI services. Huge successes have been made in this regard; however, my analysis indicates that neo-colonial approaches shaping the historic dominance of bio-medical, verticalized, NTD programme design still remain, and chronic aid dependency in Liberia continues. Thus, the longevity of the drive toward integrated, person-centred approaches to DMDI in Liberia is largely at the discretion of donors

and implementing NGDO partners. There is no single solution to addressing this neo-colonial influence on health systems development in Liberia, and it is something which the global health community needs to think critically about. Country ownership and systems design that responds to national priorities and reflects the values, needs and experiences of people affected by NTDs, their households and communities, is vitally important to ensure that DMDI strategies are truly person-centred and address unnecessary, avoidable, unfair and unjust differences in health outcomes for the most vulnerable.

Appendix 1: Key Informant Interview Guide(s)

NTD Specific Informants

Prior to all data collection participants will be provided with the information sheet and informed consent obtained. If informed consent is not obtained no data collection will take place with that individual.

Introduction to Interview

Thank you for agreeing to take part in this research study. The objective of this interview is to understand more about disability in Liberia. We would also like to better understand the links between disability and onchocerciasis, leprosy, buruli ulcer and lymphatic filariasis and specific programmes designed to support people living with these diseases.

Participant Characteristics

Interviewee ID:

Date of Interview:

Gender:

Age:

Topic Guide

Background to Participant

- Can you tell me about your organisation? (ONLY IF NON-MoH staff)
    - What are its main objectives?
    - What targets are you working towards?
- What is your job role?
    - What are your key roles and responsibilities?
    - How long have you been in this role?

Disability and NTDs in Liberia

- **How would you define disability?**
- **Can you tell me about the context of disability in Liberia?**
    - How are people living with disability included/excluded?
    - What support services are available for people living with disability?
    - How does the health system support people living with disability?
        - Are there specific health systems interventions?

- What specific support organisations for people living with disability are you aware of?

- **Can you tell me what you know about the links between neglected tropical diseases and disability?**
  - Prompt specifically for: LF, Buruli Ulcer, Onchocerciasis, Leprosy
  - How do these diseases affect people who are living with them?
    - Economically, socially etc.
  - How is the impact of these diseases monitored and tracked by the NTD programme and wider health system?

Policy for disease management, disability and inclusion

- **Can you tell me about the key policies and or guidelines influencing the NTD programme?**
  - Which policies and or guidelines have particular influence on disease management, disability and inclusion for people affected by NTDs?
    - Integrated disease case management plan? NTD master plan?
  - How do these policies link to other policies and guidelines that focus on the rights of people living with disability in Liberia?
  - What are the core areas focused on within these policies and or guidelines?

- **Can you describe how these policies and guidelines are developed?**
  - Who are the key actors involved in these processes?
    - Government officials? Health workers? People affected by NTDs? Communities?
  - How often are they refined?
  - How is evidence and programme experience used in making policy decisions?

- **To what extent do you think policy generation is influenced by international decisions?**
  - Political, socio-cultural, economic?

- **How do policies and guidelines influence the way disease management, disability and inclusion activities are planned at the national and/or county level?**

- How are such policies and guidelines communicated to the county and district level?

Policy Implementation for disease management, disability and inclusion

- **Can you describe how the polices and guidelines you mentioned are implemented at the national and county level?**
    - What activities does the NTD programme conduct to support people affected by NTDs?
        - Specifically: LF, Buruli Ulcer, Onchocerciasis, Leprosy?

- **Who is involved in the design and development of disease management, disability and inclusion activities?**
        - People living with the diseases, health workers, communities?
        - Can you describe how the community is involved in the delivery of the NTD programme?
        - How are these individuals recruited? Trained? Incentivised?

- **What works well about these activities?**

- **What are the bottlenecks in the delivery of these activities?**

- **Which disease management and disability inclusion activities are being implemented together for different diseases and which are stand alone?**
    - What are the benefits to co-implementing certain activities?
    - What are the challenges to co-implementing certain activities?
    - How are resources allocated differently for DMDI between the different diseases?

- **To what extent do you work with the health systems to implement these activities?**
    - Primary health facilities?
    - What works well?
    - What are the challenges?
    - How could collaboration with the health system be enhanced to ensure mutual benefit?

- **To what extent do you work with other actors who are focused on disability inclusion to implement these activities?**
    - NGOs, CBOs, DPOs
    - What works well?
    - What are the challenges?
    - How could collaboration with other actors be enhanced to ensure mutual benefit?

- **What are the key challenges in relation DMDI?**

- **What are the key successes in relation to DMDI?**

- **What three things would you do to better support people living with or affected by NTDs in Liberia?**

Thank you very much for taking the time to answer my questions, do you have any questions for me?

Non-NTD Specific Informants

Prior to all data collection participants will be provided with the information sheet and informed consent obtained. If informed consent is not obtained no data collection will take place with that individual.

Participant Characteristics

Interviewee ID:

Date of Interview:

Gender:

Age:

Topic Guide

Background to Participant

- Can you tell me about your organisation? (ONLY IF NON-MoH staff)
    - What are its main objectives?
    - What targets are you working towards?
- What is your job role?
    - What are your key roles and responsibilities?
    - How long have you been in this role?

Disability and Mental Health in Liberia: Context

- **How would you define disability/mental health?**
- **Can you tell me about the context of disability/mental health in Liberia?**
    - How are people living with disability/mental health conditions included/excluded?
    - What support services are available for people living with disability/mental health issues?
    - How does the health system support people living with disability/mental health issues?
        - Are there specific health systems interventions?
    - What specific support organisations for people living with disability/mental health issues are you aware of?
- **Can you tell me about the priority areas for mental health/disability in Liberia?**
    - Trauma, GBV etc.
    - Who determines these priority areas?

Disability and Mental Health: Funding Flows

- **What are the major funding flows for disability/mental health in Liberia?**
    - Major donors, resource allocation through the MoH?
- **Can you tell me what you know about the links between chronic disease conditions/disability and mental health in Liberia?**
        - Specifically NTDs.

Vignettes from the Data: Possible Solution Development

Case Study One: Dispersed Mental Health Needs

Case Study Two: Mental Health Needs as part of in-patient care

Case Study Three: Long term need for psycho-social support

- What do you think can be done to support this individual?
- What would success look like in changing their narrative/personal circumstance?

Appendix 2: Case Study Topic Guides

Illness Narrative Guide

Prior to all data collection participants will be provided with the information sheet and informed consent obtained. If informed consent is not obtained no data collection will take place with that individual.

Introduction to Interview

Thank you for agreeing to take part in this research study. The objective of this interview is to understand more your experience of living with (INPUT NAME OF DISEASE PARTICIPANT IS LIVING WITH; BIG FOOT, RIVER BLINDNESS, LEPROSY, BURULI ULCER/IF SPECIFIC DISEASE NOT KNOWN DESCRIPTION OF CLINICAL SYMPTOMS ASSOCIATED WITH DISEASE OF INTEREST; E.G. VISUAL IMPAIRMENT, LYMPHODEMA/HYDROCELE ETC.). We would like the interview to be very much guided by you as we are really interested in your story. I have a few key questions to guide our discussions but please feel free to talk about whatever you wish that relates to your experience.

Participant Characteristics

Interviewee ID:

Date of Interview:

Gender:

Age:

Clinical symptoms associated with disease:

- Can you tell me about what you know is the cause of your symptoms?

Disease of interest:

- Have you ever received a diagnosis of what causes your symptoms?
    - If yes, what was the diagnosis? Where did you receive this diagnosis from?

Illness narrative focus areas

Topic/Key Question *These should be asked as the broad opening question to the participant.*	**Theme** *These are areas that the researcher may want to use to prompt the participant if they find it difficult to tell their story. Not all areas need to be asked about.*
Life history prior to illness/Can you tell me about your life before you were diagnosed with (insert name of disease of interest if diagnosed/clinical symptoms if not diagnosed)?	Birth and growing up (beliefs, religion, childhood experiences) Household income/livelihoods Marriage/relationships/family and friends Education and employment Community interactions (involvement in the community, decision making etc.)
Experience of illness/Can you tell me about your symptoms? NB: add name of illness/symptoms using local terminology in here.	Awareness/knowledge/first memory of illness Interaction with health care services (testing, diagnosis, treatment seeking, other support services) Influence on mobility and self-care (washing, dressing etc.)
Life after/with illness/symptoms. Can you tell me about how your life has changed because of your illness/symptoms?	Positive/Negative affects Influence on education and employment/livelihoods (ability to learn new things and use existing knowledge) Interactions with the community and social life (involvement in community activities and decision making) Stigma Domestic life (role within the household; household tasks) Marriage/relationships/family and friends Ability to manage self-care (washing, dressing etc.) alone/with assistance
Looking forwards/ Can you tell me what hopes you have for the future?	More information Improved access to health/support services

During the illness narrative the following types of probes will be used to increase depth of information

- How did that make you feel?
- What do you think about that?

- Who was involved in that?
- Where did you feel able to do that?
- When did you feel able to share that?

Following the interview, arrange time and location for follow up interview with participant.

In-Depth Interview Guide: Affected Members of the Household

Prior to all data collection participants will be provided with the information sheet and informed consent obtained. If informed consent is not obtained no data collection will take place with that individual.

Introduction to Interview

Thank you for agreeing to take part in this research study. The objective of this interview is to understand more your experience of living with (INPUT NAME OF DISEASE PARTICIPANT IS LIVING WITH; BIG FOOT, RIVER BLINDNESS, LEPROSY, BURULI ULCER). We would like the interview to be very much guided by you as we are really interested in your story. I have a few key questions to guide our discussions but please feel free to talk about whatever you wish that relates to your experience.

Participant Characteristics

Interviewee ID:

Date of Interview:

Gender:

Age:

Relationship to person with disease of interest:

NB: Focus on disease of interest terminology or symptom terminology in questions will be known based on description during initial interview with person living with one or more NTD.

Experience of the Disease of Interest

- **Can you describe how (INSERT LOCAL NAME OF DISEASE MEMBER OF HOUSEHOLD AFFECTED BY/DESCRIPTION OF SYMPTOMS) affects the way you interact within the household?**
    - Interpersonal relationships?
    - Household decision making?
    - How is this the same and how is this different for different household members?

- **Can you describe the impact on the household of (INSERT LOCAL NAME OF DISEASE MEMBER OF HOUSEHOLD AFFECTED BY/DESCRIPTION OF SYMPTOMS)?**
    - Roles within the household?
    - Income of the household?
    - Education and employment of household members?

- **Can you describe how (INSERT LOCAL NAME OF DISEASE MEMBER OF HOUSEHOLD AFFECTED BY/DESCRIPTION OF SYMPTOMS) affects the way you and your household interact within the community?**

- How do people in the community react toward you and other members of your household?
- How do other members of the community support your household?

- **How would you best describe the impact of (NAME OF NTD/SYMPTOMS) on (NAME OF INDIVIDUAL IN THE HOUSHOLD LIVING WITH NTD)?**

- **How would you best describe the impact of (NAME OF NTD/SYMPTOMS) on you?**

NTDs and Disability

- **What do you understand by the term disability?**

- **How is disability perceived within your community?**

- **To what extent do you consider the impact of (NAME OF NTD/SYMPTOMS) disabling?**

Knowledge of Disease of Interest

- **Can you tell me what you know about (INSERT LOCAL NAME OF DISEASE MEMBER OF HOUSEHOLD AFFECTED BY/DESCRIPTION OF SYMPTOMS)?**

  - What are the causes of this disease?
  - What are the signs and symptoms that you have this disease?
  - How is this disease transmitted?
  - How would you avoid this disease?
  - How do you know if someone has this disease?
  - What is the treatment for this disease?
  - How is this disease perceived by the community?

- **Where did you get the information that you shared with me about (INSERT LOCAL NAME OF DISEASE MEMBER OF HOUSEHOLD AFFECTED BY/DESCRIPTION OF SYMPTOMS)?**
  - Radio, TV, Newspaper, specific individuals?

- Which method do you think gives the clearest understanding of **(INSERT LOCAL NAME OF DISEASE MEMBER OF HOUSEHOLD AFFECTED BY/DESCRIPTION OF SYMPTOMS)?**
    - Can you explain why?

- **What other information would you be beneficial to you about (INSERT LOCAL NAME OF DISEASE MEMBER OF HOUSEHOLD AFFECTED BY/DESCRIPTION OF SYMPTOMS)?**
    - What are the best ways to communicate this information?

Provision of social or medical interventions

- **What medical or social interventions have (NAME OF INDIVIDUAL LIVING WITH NTD) or your household received as a consequence of (NAME OF NTD/SYMPTOMS)?**
    - Who provided these interventions?
    - Where were they provided?
    - How were you involved in the delivery of these interventions?
    - What was good about these interventions?
    - What could be better about these interventions?
    - How much did you have to pay to access such interventions?

- **What interventions would better support you and your household?**
    - Who would you like to deliver these interventions?
        - Community, health service, etc.
    - How would you like to be involved in the delivery of these interventions?

- **What community structures could be used to deliver these interventions**?
    - What would be beneficial about these structures?
    - What would be challenging about these structures?
    - Are there any sections of the population that would be missed in using these structures?

Thank you very much for taking the time to answer my questions, do you have any questions for me?

Appendix 3: Case Study Summaries

The following case study summarises are shortened from accounts developed during the analytical process to ensure the protection of participant identity.

Maryland Case Studies

Case Study Summary CS001

NB: This case study was collected at the main referral hospital in Maryland County. The patient had come to speak to us and the interview was completed in the NTD Focal Points office. As a result, we were unable to speak to any other members of the patient's household.

Female aged 26-49 years old living with Buruli Ulcer. Widow. Clear ulceration on right arm, which had waisted, and she was no longer able to straighten. The NTD focal person described that he was unsure that she would be able to straighten the arm again or at least was unlikely to resume full movement even if the ulceration was treated. The participant described a complex care seeking pathway having been resident in Ivory Coast and trying to seek treatment there, following a confusing and unsuccessful treatment process, where there was suggestion of arm amputation, she had decided to move back to Liberia to seek treatment. This decision was influenced by her mother. Her sister had left her family and moved to Liberia with her to support her in seeking treatment and in household activities. She described here sister as her main caregiver. Her three children had also moved back to Liberia with them. The participant was known to the NTD programme, and regularly travelled a long distance from her community to the main referral hospital in search of treatment. The NTD focal point expressed frustration that they had been unable to secure medicines from the central level to treat this patient despite constant interaction with the national NTD programme, highlighting bottlenecks in the drug supply chain. The participant was particularly concerned about the impact the illness was having on both her sister and her children (who she could no longer pay for education for).

Case Study Summary CS002

Female aged 25-49, living with severe lymphoedema in the left leg. The symptoms began when she was a child in 1995 during a period of conflict. Her father carried her to the main referral hospital in Maryland county where on her second trip she was told she had a worm inside her. Due to the sickness she stopped going to school. This case study was completed in Maryland county. The patient had lived here her whole life. We also spoke to her two brothers as part of the case study interviews. Both brothers described feeling worried for their sister as well as fearful that they may also catch the sickness. One brother was physically disabled as a result of a road traffic accident.

Case Study Summary CS003

Male aged 68 years old living with lymphoedema in both legs (right severe and left moderate) and hydrocele. Participant identified his sister as main caregiver/person of importance that we should also talk too. Participant has six children, two have passed away and the other four live far away/left. He is a widower, wife died in 2004, before the sickness (began in 2007). The participants sister also talked of not being in excellent health, describing living with a chronic cough and having previously been diagnosed with TB. She is also a widower. Both described having no education and no fixed form of occupation or income. Case study was taken within Maryland county, participant described moving back here from Grand Cedeh during the conflict. '*He said the war, the 1990 war crisis came that what brought him down, he and his children'.*

Case Study Summary CS004

Female aged 25-49, living with lymphoedema that could be described as moderate in the right leg and mild in the left leg. Her and her husband, who was the other person interviewed as part of this case study, have one child. They described a want for another child, but had been unable to conceive, the husband within the case study attributed this failure to conceive to the 'big foot' for which they were seeking treatment. The participant was married to the town commissioner who she had met after the illness began. Throughout the interview, the husband appeared very supportive of his wife, expressing that she had the sickness before they met so this could not shape the way he felt about her. The housing and appearance of the family home and setting indicated that there were relatively better off than others in the community, perhaps because of his job role. The illness began when she was in 3rd grade which led her to drop out of school, she described feeling a sense of loss linked to this, which was frequently triggered when she saw children in school uniform.

Case Study Summary CS005

Female, over 49, who had been diagnosed with leprosy and had lesions on both legs. She was a widow and living with her aunt and her husband, who were her main 'caregivers'. She had been living with symptoms of leprosy for about one year. She described having been a farmer her whole life which led her to move around to make money to be able to send her children to school. When the leprosy started she had been living in a different town, however her aunt brought her back to Rock Town when she got sick, which is where she was born. We spoke to her nephew to complete the case study as this was who she identified we should interview. Her nephew described economic hardship in the household and that they were very reliant on their farm produce to survive. He described the lack of having a 'big job' as due to the fact that his father was blind, which had caused him to leave school without graduating in 1987. She described 'taking tablets' that had been prescribed to her by the Rock Town clinic and having to return for more of these tablets on a

monthly basis. When asked what the tablets were for, she said that she wasn't sure, but knew they were for her foot problem.

Case Study Summary CS006

Male, aged 25-49, living with hydrocele, unmarried. The sickness started two years ago. The case study was taken in Maryland where the participant was born and lives. The participants brother was the other person interviewed as part of the case study. Prior to getting sick the participant was a fisherman and would fish daily leaving from the community between 7am and 4pm. He had sought treatment at the hospital several times for the illness and was told to return for an operation in June. The participant described having gone to school until secondary school level but had dropped out in 11th grade due to being unable to afford school fees. He had travelled to attend secondary school in Plebo and Harper (main towns in Maryland county). His brother described a fishing accident that had injured his brothers' hand and following which he hadn't been the same since, he sounded like he was describing some elements of PTSD or depression associated with the event. Hydrocele in this case, could be seen as a co-morbidity with pre-existing mental health challenges.

Case Study Summary CS007: excluded at participant request

Case Study Summary CS008

Male, aged 25-49, living with severe lymphoedema in right leg. Participant is married, and his wife was the other person interviewed as part of this case study. They are living in Maryland, and have had three children, but one has died. The illness began in 1994 before they were married or knew each other. This was during the war time, '*where there were no medicines available'*, and so he had to seek medicines from the country doctor in exchange for the payment of a cow. The country doctor was based in Ivory Coast and was seen by the participant as their only option during this time. This treatment involved cutting in the skin. Since that time, the participant has taken many medicines for pain management, predominantly Panadol. He described leaving school because of the sickness and was unable to have the 'upper hand' unlike some of his siblings.

Nimba Case Studies

Case Study Summary CS009

Male aged 18-25 years old, living with the effects of leprosy, specifically gnarling on left and right foot. Treated as an inpatient at leprosy treatment centre and returned to the community. He had been given shoes at leprosy treatment centre to aid him in walking. Participant identified his wife as the other person that we should talk to as part of the case study. She was 25-49 years old and living with leprosy. The case study was completed in Nimba county, in Lepula community. The patient had lived here his whole life, whereas his wife had moved to the community with her mother because of her marriage. They had then met and married before

the leprosy had developed. Together they have had five children, but the officer in charge of the health facility informed us that each time she gives birth the family and community describe that she is too sick to look after the baby so they take the baby from them, each time the baby has subsequently died (they think because of a lack of milk etc). Together they both experienced high levels of stigma and social isolation. They both seemed to crave social interaction and a want for friends and social acceptance. The patient had a dog that he was very attached too and went everywhere with them.

Case Study Summary CS010

Male, aged over 49, has problems with his feet and gnarling on both hands, with some fingers missing because of leprosy. He described that his hands and feet were left feeling numb and he also had difficulty in seeing from one eye. We were unable to identify anyone in his current surroundings to speak to despite description throughout the narrative that the relationship with others in the household was fine now. The illness began in 1979 where he sought treatment at the hospital and was told repeatedly that he had malaria/filaria and was treated accordingly. At this time, he was living in Monrovia and working for a large steel company. He had moved to Monrovia from Nimba county, where he had been living with a man known to the family who was supporting him through school. He moved to Monrovia to earn money. In 1999, during the conflict, he was in Ivory Coast, where they told him that he had leprosy. When he returned from Ivory Coast in 2000, he went straight to the leprosy treatment centre, where he was treated for Leprosy for 4 years and 10 months, returning to the community in 2004. Throughout the narrative he is very specific with dates of events.

Case Study Summary CS011

Female, over 49, living with mobility restrictions in her left leg and vision problems in her left eye as a result of leprosy. She was a widow and described the death of husband before she got sick. The participants sister was the other individual included in this case study who she now lived with and appeared to have a close relationship with following the death of her husband. She had been treated as an in-patient for Leprosy in 2003, having been referred from the clinic in her community. At the point of treatment seeking she had been living with symptoms of leprosy for 10 years. She described a happy childhood with a small family, she had married young when her father accepted a proposal for her. Once married, her and her sister described her as a breadwinner within the family, particularly because she could *'hunt like a man'.* Leprosy had impacted both her and her sisters' life quite dramatically, particularly in terms of their economic status, now very reliant on handouts from the community, who they used to support, and who now don't want to provide things for them for free. Throughout the narratives there were intersections with age in terms of social exclusion and interactions with the community.

Case Study Summary CS012 and Case Study Summary CS018 (these participants were married and so both were interviewed as well as CS012's daughter)

Male, over 49, experience of gnarling in both hands and problems with his feet as a result of Leprosy. His wife (person affected linked to CS018), is also living with the effects of Leprosy, specifically, having lost one foot and on crutches and also some gnarling in both hands. She is also over 49. Both are living in a peri-urban settlement just outside the leprosy treatment facility which was a previous leprosy colony. The couple had met following Leprosy treatment and married at this time. He found comfort in the fact that they had both experienced Leprosy stating that *'you are sick, I am sick, when you and I are together, I will not feel hurt'* (CS012). We also spoke to his daughter to complete the case study and asked both participants about the experience of their spouse. The information that the participants daughter could provide us with was limited as she had been told for most of her life that her father had died as he had been forced out of the community following Leprosy treatment. She had only recently come to find her father but was able to share information about how she felt about the situation and the impact the 'loss' of her father had had on her. The interaction between the participants and the daughter provided detailed information about the shared experience of leprosy and what it was like living in Wuo Town. The male participant translated at times for his wife, he also sometimes added information to her story, but did not appear to restrict the experiences she shared, although may have limited any negative description of their interpersonal experience.

Case Study Summary CS014- see Box 7- Hannah's Story

Case Study Summary CS015

Male, over 49, blind following onchocerciasis. When he first got sick it was the war time so he described spending 2 years trying to seek help at the country doctor before going to the hospital. He had to leave school due to the sickness. He was married and described that it is his wife who is looking after him now. He described living in a constant cycle of debt where they would pay one person back for something and then have to gain credit from someone else. Borrowing money was common to pay for their son's school fees, food or medical expenses. His wife had previously been married to his brother, however when his brother died during the conflict they had married as this was customary. He was already blind at this point. The wife described finding it distressing to look after her husband and that people in the community would sometimes talk badly to her because of him being blind- she it was a curse or witchcraft. They described wanting a poultry farm to help reduce the amount of debt experienced.

Case Study Summary CS016 – Excluded non-NTD case study, only became apparent during narrative.

Case Study Summary CS017

Female, 25-49, treated as an outpatient for Buruli Ulcer and had no physical limitations remaining. Had been ill with leprosy as a child. This participant was living alone with her young daughter and could not identify anyone with whom we could also do a household interview. She was a fufu seller in the market and asked us to also visit her there for her follow up interview. When asked about her interactions with the community and her family she became very emotionally distressed describing that there was no one around her anymore as they had either died or left her alone. She was living in a one room dwelling and described doing all she could to support her daughter to go to school. She described struggling to stand as it caused her pain if she stood too long and so preferred sitting. She described the cause of her disease as being linked to something that happened to her on her cassava farm as when she returned she had a blister and burning feeling in her leg that meant she couldn't sleep. Throughout the interaction she described changes in the community that had made her feel sad, she attributed changes to the war. For example, before the war when she received leprosy treatment this had all been free, however now when she went to access services she had to pay. She also described that everyone used to know and support each other within the community but that this had stopped since the war time.

Case Study Summary CS018- see summary CS012

Case Study Summary CS019

Male, 25-49, some gnarling in his hands, skin discoloration and problems with sight as a result of Leprosy. Currently being treated as an in-patient at leprosy treatment facility. Has never been to school and was engaged with farm work in community before he got sick. His symptoms began in 2016 where he sought treatment at the traditional healer as he thought the illness was due to 'African signs'. He described seeking treatment at the country doctor as it was what his parents would do. This cost the family a significant amount of money in cash and in items such as chickens which led to him feeling bad. He described the need for treatment and feeling ill consuming all his daily activity. When treatment failed here, another member of the community told him to travel to the leprosy treatment facility where they would have treatment for what he was experiencing. The journey to the facility cost 20USD where he was now receiving in-patient treatment and focused on getting well. He had concerns about the impact of the disease on his ability to complete 'hard work' or farming when he returned to the community. He also described being reliant on his uncle to visit him for company and money as his father was sick and mother too far away

Case Study Summary CS020

Female, 18-25, sore on foot because of leprosy, been a patient at leprosy treatment facility for 2 years and 4 months. Prior to illness was living in a house with a woman who was violent towards her because she could not contribute to the household as much another girl who was given money by her boyfriend to contribute. The

woman who owned the house suggested that she engage in 'man business' (sex work) to be able to contribute. She was involved with one man who got her pregnant and then left her, where she had to return to her grandmother's house to give birth. She described having given birth in her grandmother's house and that when her father had been told about the birth he was very angry, refused to believe it and threatened to kill her with a cutlass (large knife used for farming). Originally from Ivory Coast, travelled for treatment, found it difficult to express story properly in the languages available. Prior to coming to leprosy treatment facility, she described that people were already beating her and trying to force her from the community when she experienced symptoms. As a result, following a failed attempt to visit the facility and then the herbalist (when instructed by her uncle), she described leaving her grandmother's home to travel to the leprosy treatment facility, she described a lot of fear around this as she had never been to Liberia before and she knew that she would lose contact with her family. This journey was made one week after giving birth. Since arriving in the facility, she has had no contact with her friends and family. Travelling to Ganta cost her 40USD, however she described liking it there because people were accepting of her and her children and they divide food and soap for them monthly: *'people at [at the treatment facility] hold and support me'*. She described a lot of fear at the prospect of having to go back to her community as she knows she will be treated as she was before. She knows it is not good for her children to spend their whole life at the hospital however if she must leave the treatment facility she would rather find a *'new place to go with them instead of going back home'*. When asked how she felt about the sickness at different point she described that '*I feel bad and think about committing suicide. Because I was not even allowed to enter the church. So, I used to go beside the church and pray with my hands on my kids'.* She described mixing water and rat poison at several points to try and kill herself but had stopped herself due to fear of what would happen to her children. She described that these suicidal thoughts had decreased since being at the treatment facility, however when she was sitting on her own, she can often begin to feel bad again when thinking about the past and future.

Case Study Summary CS021

Male, 18-25, lesions on face and arms as a result of leprosy, been a patient at leprosy treatment facility since 2016. Prior to illness was in school (eight grade), but when started getting sick, had to drop out of school. His parents were completing contract (farming etc) work to help support him in going to school. When he started experiencing symptoms, his mother took him to the country doctor. He didn't feel this was necessary as he knew no one in his family would bewitch him and he was concerned that his mother was spending a lot of money for this treatment. The disease progressed and started to appear on his face, at this point, someone also came to the community and advised that he should go to the clinic. His mother took him to the clinic in Bong county where they indicated that he may have leprosy and should go for treatment at the treatment centre as this was the only place that it

was available. When they returned to the community, his mother engaged in more contract work to be able to provide the money to take him to the facility. When they finally reached the facility and they told him that it was definitely leprosy, his mother left and hasn't returned. He described struggling with this and often can't afford to buy clothes and is reliant on someone providing these things for him. Before leaving his community, he described that people had already started to exclude him because he was sick. He described that friends stopped interacting with him and he was made to eat separately. He feared that when he was better he wouldn't be able to return to the community as he would still be treated the same. He hopes that once he is better he can be supported to make a business so that he would be able to return to school.

Case Study Summary CS022

Female, aged 26-49, partnered although described being left by partner to look after the children just before the sickness in 2009. She described been taken from school to be with this man at a young age as 'people were blind to education then'. Since she has got sick, he has not cared for her or her children. Currently a patient at leprosy treatment facility since 2016 and has challenges with her feet because of leprosy. She described the illness beginning in 2012 when she was 39 years old and a long period of four years where she made repeated visits to different health care providers to seek diagnosis and treatment. She described that this period of health seeking had cost approximately 35USD and that she had had to rely on finances and support from family and the community during this time despite trying to also complete her normal farming and selling work. During this period when the sickness was at its worst she described being unable to complete basic household tasks such as dressing and drawing water. She first sought treatment at the traditional healer who tried to use chalk to heal her, when this failed she described travelling to Monrovia and other large centres in search of treatment. She also sought a lot of advice and searched for help in various churches and she believed that god led her to the treatment facility in a dream. When she finally received a diagnosis at the treatment facility she described feeling relieved to know what was wrong with her. During her treatment at the leprosy treatment centre she described several episodes of chronic pain where she had to seek additional treatments. She also described calling her son to talk to him when she was experiencing this pain and then he tries to come and visit her at the weekends. Her other children are too young and live too far to visit her which she found particularly distressing. Prior to getting sick, she engaged in several small business activities between Liberia and Ivory Coast and she used this money to prioritise her children's education. Since getting sick, she described the main impact on her and her children was that they were no longer able to go back to school although she is trying her best to support them. She feared getting better and the challenge that this will bring of trying to start a new life for her and her children as she didn't feel like the community would accept her if she was to return.

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Case Study Summary CS023

Male, 25-49, currently an inpatient because of Buruli Ulcer. He is a cassava farmer and described returning from the swamp and experiencing sores on the skin. He went to the country doctor immediately within one week of getting sick who gave him some cream to rub on the sore. This didn't work, and the sore got bigger and burst, he became very sick and was shivering and vomiting and thought that he was going to die. A group in the community that he was part of put money together to try to help him and a friend told him that he should go to a specific treatment centre for the foot business and so that's when he travelled (about a year after the symptoms). He described that he went to the country doctor first as they are 'uncivilised people' who want to deal with the witching first. He said that although no one has been to visit him since he arrived at the facility, people have been sending him money on a motorbike to help him. He feels like when he is discharged he will be able to return to the community and he will be ok and will be happy. He described that he will try to go to the swamp less and would like to spend time selling as oppose to being on the farm. His main worry was that when he got sick he had had to sell everything to pay for treatment and he is not sure how he will look after his wife and send his children to school, especially if he is no longer able to do any hard work.

Case Study Summary CS024

Female, age 18, Buruli Ulcer patient. The ulcer was on her right leg and has left severe scaring, when she was talking to us she kept this hidden the whole time and used her left leg to describe what had been happening to her. She was living at home with her family and selling coal in the community to survive having left school in 8th grade as her family could no longer afford her school fees. She woke up one morning and her foot was puffy and swollen so her mother carried her to her uncle who made traditional medicines for her to treat her foot as they thought that it was caused by African signs. After one year when the sore did not improve, her mother carried her to her aunties house so that she could go to the facility for treatment. Her mother spent some time with her there before returning to the community. During the treatment she had an operation on her foot which cost 50USD as well as travelling to the clinic three times per week for injections and to manage her wounds. She described that the wound on her leg had healed, however she now has sore on the back of her hand. She said that she now found it hard to move about now because of the sore; she can't draw water; she can't complete household tasks and her sister must help her. Since her sickness she felt that the same friends tend not to come around her anymore which can make her feel down and even think about committing suicide but she doesn't have anyone to talk to about feeling bad like that. She described that this had improved a little since the healing of the wound on her left and that some of her friends come around her a little more again now, which has helped to reduce her feeling suicidal. During the

sickness, she also described that her family were treating her bad, she was reluctant to talk about it and didn't want to tell us how they had been treating her. She described that she was not able to talk to anyone about it. In the future she hopes to return to school so that she can progress to further education to be able to provide for her family.

Case Study Summary CS025

Male, 44 years old, has large ulceration due to Buruli Ulcer on left leg. Left Bong county in 2011 to move to Monrovia where he was working as a construction worker before the illness started. The sore started in January (two years ago) with a pain in his waist. When he experienced the pain, he talked to a friend and his brother and sister about it. They told him it was African signs and so he went in the 'sick bush'. He spent 8 months in the sick bush, but the 'medicine man' told him to go to the hospital after the wound burst 6 times. He spent about 175 USD in the sick bush. His brother described calling him to come back to Bong county for treatment where the family would be able to support him. He made the decision to return because 'my parents are here. In Monrovia it is very expensive, so I decided to come up here to get well to go back to my family'. His brother described that he is currently supporting the whole household with some contract work. In October, he went to phoebe for treatment where he had an x-ray and then was given tablets which he returns for more of when they are finished. He has been told to be patient and to wait for the NTD team to come and to see the bone doctor. There was some level of frustration as he had been waiting for this for a long time and wanted us to provide treatment for him. The need for a 'bone doctor' had caused him some confusion as he doesn't believe that anything has happened to his bone; 'I didn't experience any trauma for it to be my bone that is sore'. He described believing that the cause of his sickness is witch craft and referred to the ability of god to take it away from him. He described improving having not been able to walk for four months but slowly he can stand again thanks to god. He was however frustrated the he had now been sick for over two years. He described feeling very bad as he had had to leave his wife and children behind in Monrovia. He felt that 'because I am the man I supposed to be that thing' and worries most about his children and who will take care of them. During periods when he is feeling very bad, because his 'movement is limited, activities in life ends' can feel so bad that thinks about committing suicide. He described that some of his friend's sill come around him and talk to him and this can help him to feel better. Although his brother described that it is only friends that know him very well who will still interact with him. Some youth group members (of which he was part before his illness), got together to send him cash to support with buying food etc.

Case Study Summary CS026

Male, age 26-49, Buruli Ulcer out-patient-Phebe hospital, Bong county. He described having a relatively good life before the sickness and that someone from America had paid for him to go to school until the conflict when he stopped

because there were no funds anymore. Since this time, he was selling things in Monrovia until the sore started when he had to return to Bong county as treatment is cheaper there. He is currently selling books and he uses whatever money he makes each day to eat. Before getting sick he was living with a woman, however because of the sore his family won't let him sleep there anymore. He decided to leave the house for himself because 'if he used the same bucket they will be talking'. He described that his wife left him 'she can't be suffering under this man' I can't provide for her. We also spoke to his niece as someone who was important to him, they were clearly very close, and he had provided a lot for her schooling. They were currently living separately as the house where most of the family live only had one room, he was staying in a place nearby. Most of their other family live outside of Liberia, they left during the war and they don't have contact with them or they don't want to help him. His niece described that she wants to know more about what is wrong with him to help him as he is the only person who has been helping her with his schooling.

Case Study Summary CS027

Female, over 49, visual challenges and skin condition because of onchocerciasis. She was a widow currently living with her children in Bong county. She described being married and her husband having four wives who all used to cook and eat together. She described going to work every day on the plantations when she was younger as well as being part of the church women's group. She also reflected a lot about the only other time she had experienced illness was when she had measles as a child. Her son described the eye problem starting on his mother in 2012, however she had experienced itching before this time. The community only got a clinic in 2014, so they described being told by someone in the community that it was filaria and they should take her to the main referral hospital for the medicines. At this time, they didn't have the money to travel to Phebe. When they had enough money, the trip cost them 40USD. On arrival at the county referral hospital they were prescribed the medicines and told to go and buy them from the pharmacy, but they were unavailable. They contacted family in Monrovia to try and help in obtaining the medicines, but this was not possible. As well as 'formal' health seeking, she also described making trips to the country doctor who would give her ointment for her eyes. She described that he told her she was going to go blind because of 'sinking fontanelle' which she said she took seriously as 'if you don't then something bad can happen to you'. Her son described being educated and so not believing in the need for country medicine, however it was still important to go to the country doctor because his mother and uncle said it was critical.

She described living with her daughter who is feeding her as she unable to do any farm work anymore. This meant that she is having to depend on god now because she can't do anything anymore. Her daughter tells her that it is her duty to look after her and this was confirmed by her son who felt it was there responsibility to look after her despite the economic burden it was having on the household. Despite

receiving care from her family, she described that this can make her to feel bad because all of her friends can make pepper farm, but she isn't able and now she is just sitting with her children. She described that she wasn't sure whether this was because of her illness or old age, but that she just must pray to god that she won't go blind completely. Because of this, she was keen to take all the medicines that she was given and comes to the facility anytime she feels sick. She had told the facility staff a lot about the eye problems but less about the bumps on her skin. She described being told a lot that it was filaria after she has been given the medicine, but that she didn't know a lot about the disease itself. Her son described that some people in the community can mock at her and she talks to him about it making her feel bad. She interacts with the family fine 'only the bathing things we don't share with her', but that they try to keep the condition a secret from others because 'that's what is done in the interior'.

Case Study Summary CS028- see Box 6 Jon's Story

Appendix 4: Coding Framework

Code
Challenges with mobility
Community Interactions
- Challenges with community reintegration
- Enacted Stigma
- Fear from community of disease transmission
- Reluctance to disclose community experience
- Temporal Variation
Coping Mechanisms
- Role of Faith
Definition of Disability
- Links between disease and disability
Disease Origins, Impacts and Description
- Demand to know more about where the disease came from
- Disease Transmission
- Negative impact of the disease
- Origins of Disease
- Signs and symptoms of disease
Disrupting Life Events
Economic Burden
- Hand-mouth living
- Loss of livelihood strategies
- Payment for medicines
- Self-survival strategies
Fertility and Reproductive Rights
Gendered Roles of Caregivers
Health Seeking Pathways
- Barriers to health seeking
- Diagnosis
- Impact of Conflict
- Lack of understanding of treatment process
- Let down by health or referral
- Medical Advice Given
- Perception of severity
- Referral Pathway
- Repeated health or cure seeking
- Role of others in care seeking decision
- Role of traditional medicine
- Treatment at facility
- Un-concrete medical advice or treatment
Hopes for the future

- Donor or professional dependence
Impact on the household or caregiver
- Reliance on a wider caregiving network
Interpersonal Interactions and Relationships
- Impact on marriage/natal family
- Self-isolation/self-stigmatisation
- Geographical Variations
- Loss of social status/position
Livelihood before illness
Livelihood strategies now
Poor living conditions
Psycho-Social Experience
- Feeling of helplessness or loss
- Feeling of worry
- Suicidal Ideation
Social Support Systems
- Interactions with other patients
- Other support organisations
- Removal of support from family
- Social isolation
- Support with household tasks
- Trust in the local health system/specific individuals
Transient Impact of Disease/Flare Ups
- Trigger points

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